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### Mental health consumers' experiences of becoming evaluation researchers

Gillian L. Malins

*University of Wollongong*, [gmalins@uow.edu.au](mailto:gmalins@uow.edu.au)

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**MENTAL HEALTH CONSUMERS' EXPERIENCES OF BECOMING  
EVALUATION RESEARCHERS**

**A thesis submitted in fulfilment of the requirements  
for the award of the degree**

**DOCTOR OF PHILOSOPHY**

**from**

**UNIVERSITY OF WOLLONGONG**

**by**

**Gillian Leigh Malins**

**B.A. (Hons)**

**Department of Psychology**

**2005**

## DECLARATION

I, Gillian Leigh Malins, declare that this thesis, submitted in fulfilment of the requirements of the award of Doctor of Philosophy, in the Department of Psychology, University of Wollongong, is wholly my own work unless otherwise referenced or acknowledged. The document has not been submitted for qualifications at any other academic institution.

Gillian Leigh Malins

14<sup>th</sup> June 2005

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## ABSTRACT

There is increasing recognition of the need for mental health consumers to be fully involved in mental health research; however, there is limited knowledge about mental health consumers' experiences as researchers. This knowledge is important if genuine research partnerships with consumers are to be successfully developed. The research presented here aimed to use accounts by consumers of mental health services to develop an understanding of the experiential and psychological processes of consumers becoming researchers.

To achieve this, two qualitative studies were conducted. The first study explored the experiences of being a consumer of mental health services, through a series of focus groups and interviews. Study 2 consisted of an exploration of the experiences for mental health consumers, new to research, in becoming evaluation researchers. The themes resulting from an interpretative phenomenological analysis of consumers' accounts in the two studies provide a rich and wholistic view of the experiences of being a consumer of mental health services, and their experiences of becoming researchers. The results demonstrate that the experience of becoming a researcher was complex, with challenges, benefits, personal change and a range of emotional reactions. The results from Study 1 and Study 2 were then used to develop a model of consumers' experiences becoming researchers.

The broader implications of the understanding of consumers' experiences of becoming researchers developed in this research, for developing consumers' roles as researchers and for mental health service provision and clinical practice are discussed. Additionally, the theoretical and methodological implications of the research conducted are examined. Finally, the limitations of the research and directions for future research are discussed.

CHAPTER 1  
INTRODUCTION

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My research focuses on the experiences of consumers, their experiences with mental health services and of becoming researchers. Specifically, I have examined the experiential and psychological processes for mental health consumers new to research in becoming evaluation researchers. In this chapter, I deal with the context of the research and the theoretical and methodological approach chosen to explore consumers' experiences. I also address the terminology I have used, and finally, I provide an account of the research in the chapters that follow.

My research was grounded in a larger project, called Consumer Evaluation of Mental Health Services (CEO-MHS). A team of both academic and consumer researchers worked collaboratively on the CEO-MHS. My research focus, as I describe later in this chapter, developed from this collaboration.

### The Context and Approach of the Research

For me, the research I present here represents an extremely rewarding three years of work. I am deeply honoured to have worked with the consumers on the CEO-MHS team, and have learned enormously from both the formal and informal aspects of our interactions. I feel privileged that these colleagues allowed me the opportunity to hear their stories of being consumers and becoming researchers, and that they have trusted me to be part of their voice through my work. I hope that what follows will do justice to their faith in me.

It was essential to me that the theory I chose to approach this research with mental health consumers acknowledged my research colleagues and participants as whole, meaning-creating people, with multiple roles beyond mental health service user. Furthermore, I needed a theoretical position which accounted for, and created opportunities for, their active engagement in all of the research activities. I needed a theoretical stance and research approach that acknowledged the consumers' views and perceptions – of their experiences with services, and of their experiences becoming



researchers – which enabled them to voice their experiences in their own terms, recognising them as active meaning makers. I chose personal construct theory (PCT) as my underpinning theoretical stance, and qualitative methodologies to inform my research approach. This theoretical and methodological choice allowed me, with my participants, to explore their understandings and experiences, privileging their perspectives, while at the same time also acknowledging my role as interpreter in the research process.

Consistent with a personal construct and qualitative approach, I use the first person to report in this account. It is especially pleasing that the APA policy I am guided by as a psychologist also encourages this approach to writing. I am acutely aware in writing my account of the research that I do not currently identify as a consumer myself, as I have not had personal contact with a mental health service. I am, therefore, an outsider to the experiences my colleagues and co-researchers have shared with me, although as one colleague frequently reflected, “we are all humans” (perhaps after Deegan, 1993). I also believe I can claim some commonality as a ‘beginning’ researcher myself. My interpretation of their experiences will inevitably reflect this ‘outsider’ perspective, to some extent, and I believe that using the first person to report my account assists in making transparent that this is my interpretation.

My exploration of the experience for mental health consumers in becoming evaluation researchers occurred as part of the larger CEO-MHS project, and my research focus emerged and was shaped during our interactions. The research team included a management committee, with consumer representatives and academic staff members forming this group, a project officer, consumer researchers, myself, and several other students who were involved in aspects of the CEO-MHS research at different times. The research presented here developed as an idea through a number of discussions I had with various other members of the team. The team became aware that a gap in our research documentation and process was any recording or exploration of the process and experience for the consumer researchers. At least one consumer researcher suggested not

long after the CEO-MHS data collection commenced that she thought it was vitally important that their stories be told, suggesting that I could focus on this as a part of my thesis.

In conducting this research, I worked from a particular view. Firstly, I worked from a position, grounded by personal construct theory, that people actively make meaning of their experiences. As a starting point, this led me to explore qualitative methods for hearing and understanding the consumers' views: to try to understand their experiences from their perspective. Also, an assumption that guided the research design was that to understand the experience of becoming a consumer researcher, I should also try to gain insight into the experience of being a consumer. This led to the development of Study 1, as it is presented here, and which I use as a foundation for understanding the experiences of the consumer researchers. My approach has also been influenced by the values on which we acted as a team, and which we endeavored to explicate during our work over the three years as underpinning the CEO-MHS approach (Malins et al, 2005). These values include:

- Consumers' as experts – valuing lived experiences;
- Consumer participation – giving consumers a voice;
- Working for continuous improvement of the broader community: mental health services, consumer status within mental health services and the community; and roles for consumers;
- Empowerment - challenging and acknowledging existing power structures at all levels and creating environments for personal empowerment;
- Power through sharing knowledge and experiences; and
- Working together, collaboration.

The CEO-MHS team believed these values captured the way we had worked together, and represented the underlying aims of our research effort, as well as being

values that should underpin any consumer evaluation of mental health services. These values are interconnected: Cogan (1998), for example, describes the inclusion of consumers' voices in the design, delivery and evaluation of mental health services, or services research as taking a "consumer as expert" stance. This, she argues, is also known as "empowerment." She states that "an empowerment approach advocates that all individuals have the ability to shape events within their lives rather than remain powerless and helpless, and thus, people with serious mental illness should be an intricate part of their own treatment and rehabilitation." (1998, p. 145). These values, both implicitly and explicitly, are part of my work and my desired approach to conducting the research.

My research brings together a number of key areas: the phenomenology of using mental health services; evaluation of services; mental health employment; consumers' roles in research; participation; and recovery. What is presented has implications for understanding each area. Currently Australia is facing another select committee inquiry into the provision of mental health services across the country. The issues raised in my research are salient to those discussed by witnesses to this senate inquiry (Commonwealth of Australia, 2005).

In recent decades, there has been a call for more research oriented towards investigating and understanding the subjective experiences of people with diagnoses of mental illness (Davidson, 2003). Consumers' views of what works in services and what does not, their experiences of using mental health services and of living with a diagnosis of mental illness are increasingly recognised as essential information for services to understand, and are being more regularly sought (Corrigan & Penn, 1997; Crawford, 2001; Knight, Wykes & Hayward, 2003; Perkins, 2001; Wykes, 2004). The recovery literature has also emphasised the importance and usefulness of more subjective, first person knowledge and understanding in the mental health field (Ridgway, 2001). As Davidson, Stayner, Chinman, Lambert and Slade (2000) state, qualitative, and phenomenological investigations play an important role in developing new and relevant

understandings and approaches to mental health service provision, and “will prevent us from simply rehashing our own preconceived, largely medical notion of disorder, and will assure the relevance of our interventions to our patients’ ‘day-to-day’ lives.” (p. 154). Qualitative and phenomenological explorations of consumers’ experiences, however, remain limited in the mental health field (Davidson, 2003). The research I present in the following chapters is an important contribution to our understandings of consumers’ experiences, as people using mental health services, and as people living with a diagnosis of ‘mental illness’. Additionally, this research is a useful contribution to the qualitative literature, and demonstrates the utility of qualitative and phenomenological methods as constructive tools that contribute to the mental health field. The research also holds important implications for evaluating mental health services.

Employment is identified by consumers as a priority (Lord, Schnarr & Hutchinson, 1987; Young, 2001), and is well established as having a significant role in promoting and maintaining mental health. Additionally, a range of negative consequences are known to be linked to not having work. However, in Australia, the unemployment rate for people diagnosed with a psychotic illness has been around 72% for a number of years, and Sane Australia report that for those consumers who are working, often their principal income remains the disability pension (Sane Australia, 2003<sup>a</sup>). From a more global perspective, the World Health Organisation (WHO) state that “the unemployment rate of this group is around 90% - in contrast to that of persons with physical or sensorial disabilities, which is approximately 50%.” (Harnois & Gabriel, 2000). As the WHO state “for people with mental health problems, finding work in the open labour market or returning to work and retaining a job after treatment is often a challenge. Stigma surrounds those with mental illness and the recovery process is often misunderstood.” (Harnois & Gabriel, 2000, p. 4). A number of barriers to gaining and maintaining employment have recently been identified by Killeen and O’Day (2004) based on the

experiences of 32 consumers at different points in the process of working or looking for work.

The World Health Organisation suggests that changes in the labour market over recent decades have increased the need for consumers to have opportunities to re-train if they want to re-enter the workforce after a break. The once more readily available ‘low-tech’ positions are not as common. I also suggest that these low-tech positions are unlikely to be suitable or appealing to the range of people who are consumers, and it is important that a variety of genuine employment alternatives are available (Biggs, 2000; Grove, 1999; Handler, Doel, Henry & Lucca, 2003; Killeen & O’Day, 2004; Sane Australia, 2003<sup>a&b</sup>). Greater understanding of different work opportunities and what these mean for consumers are needed, and more pathways to employment need to be considered and found. The findings I present here are important within this context.

The specific type of work situation explored in my research – consumers being employed to work as researchers in the mental health field – is therefore, also centrally important. As I will detail in the chapters that follow, there is a growing call for consumers of mental health services to be involved in research. Thornicroft et al (Thornicroft, Rose, Huxley, Dale & Wykes, 2002) report results of consultation in 2002 with mental health service consumers in London, during which consumers’ priorities for service development and research were sought. The main priority identified by consumers in this consultation was specifically about involving consumers in all stages of the conduct of research projects. What the experience of working in mental health research is like for consumers is, however, as yet a relatively unexplored area (Carrick, Mitchell & Lloyd, 2001; Henry, Nicholson, Clayfield, Phillips, & Steir, 2002; Rhodes et al, 2002; Telford & Faulkner, 2004). Telford and Faulkner (2004) recently concluded that more information is needed on the impact of involvement for consumers, and Rose (2003) has argued that while collaborative research between consumers and academics is becoming a more mainstream expectation, little is known still about collaborative research.

The Australian National Health and Research Council (NHMRC) and Consumers' Health Forum of Australia have published a statement on consumer and community participation in health and medical research (2001). This states that:

as the users of health and medical services, consumers can provide valuable input to health and medical research. If such research is to continue to provide high quality outcomes, it is important that consumer involvement in research and its ongoing development is facilitated. This includes participation by consumers as equal partners in the development of research goals, questions, strategies, methodologies and information dissemination. (p. vi)

Similar policy is evident in the United Kingdom (Department of Health 1999,<sup>a</sup> 2000). However, to achieve this equal partnership, skills need to be built and remuneration needs to occur (NHMRC and Consumers' Health Forum of Australia, 2001). Consumers need to be provided with genuine equality, not equality in name only. The research I present in the following chapters is important in adding to our understanding of consumers in research, specifically in the mental health field, by providing a detailed exploration of the experience for ten consumers of becoming a mental health evaluation researcher.

Consumer participation in all aspects of mental health services is also one of the national standards for Australian Mental Health Services (Australian Health Ministers, 1997), and similar policy exists in the US (US Department of Health and Human Services, 1999, 2001) and UK (Department of Health, 1999<sup>b</sup>, 2001). In 2002, Stacey and Herron reported on an evaluation of enactment of Australian mental health policy regarding participation, and outlined a range of barriers that contribute to continued limited enactment of participation policy. One barrier they described as a "continued need for consumers ...to have access to education, training and contemporary debates that enable them to increasingly engage in a range of areas in the mental health field." (Stacey & Herron, 2002, p. 7). I argue that to involve consumers in mental health research, with training in research principles and skills and access to the range of resources including

literature and websites that this entails, is an essential component of ensuring there is a full range of opportunities for consumers in the field, and an important opportunity for consumers to become educated and knowledgeable and enabled to fully participate.

Stacey and Herron suggest there is a need for “ongoing structural and cultural change in order to progress from consumer participation as ad hoc and token to committed systemic practice” (p. 7). Without consumers genuinely involved in determining and enacting the mental health research agenda this cannot occur. As Church asserts: “consumer participation is about power and the redistribution of power” (1996, p. 29), and for real power redistribution, the opportunity for consumers to be involved in, and, to make decisions about, research conducted in the field of mental health is essential.

## Two Studies Exploring the Experiences of Consumers of Mental Health Services

### Becoming Evaluation Researchers

My challenge in this research is to develop a model of mental health consumers becoming evaluation researchers, using consumers’ accounts of their experiences as users of services and of becoming researchers, and personal construct theory. I have also attempted to live out the values described above, in the way I have conducted the research. To achieve this, I have conducted two qualitative studies.

In the first study, I explored consumers’ accounts of using services, to develop an understanding of the experiences of being a mental health consumer. In the second study, I used accounts of Consumer Researchers (CRs) from the CEO-MHS team, to develop an understanding of the experiences of becoming a researcher for these consumers. I then used the findings from these two studies, and personal construct theory, to develop a model of mental health consumers becoming evaluation researchers.

### Terminology

It is important for me to acknowledge that, while I have used the term consumer for consistency in my research account, this term is not universally adopted by people

who use/have used mental health services (Telford & Faulkner, 2004). There is strong debate and differing opinions about which term is preferred, reflective of the dynamic variety within the broader consumer movement (Epstein & Olsen, 1998). An Australian study conducted in 2001 found that while respondents preferred health professionals to use the term client, there was a treatment setting effect relating to the term reported as preferred by people using mental health services (Lloyd, King, Bassett, Sandland & Savage, 2001). Some authors use a combination of terms to capture a broader range of preferred identities: consumer/survivor/ex-patient (Acuff, 2000; Kaufmann, 1999). The term consumer, however, is recognised generally as the most widely adopted in Australia (Sozomenou, 2000). As a team, the consumers working on the CEO-MHS project and I discussed the issue of language and labeling on a number of occasions, and it was evident to me during these discussions that a range of views on the term consumer were held within the group. They chose and agreed to use the term ‘Consumer Researcher’ as their title, but some members of the team appeared more frequently to use the term ‘Research Assistant’ to describe their role. I see this as one of the limitations of language, in attempting to discuss and communicate about a group of people with common experiences or interests, without labeling and stigmatizing: this is a pertinent issue in the mental health field.

### The Research Report

In Chapter 2, I describe the context within which this research is placed, providing a description of the CEO-MHS project, and the consumer researchers’ roles in it. As well, I review existing literature on evaluation and consumer participation in mental health research in Chapter 2. In Chapter 3, I explore the literature describing theoretical models of mental health and illness, examining the implications and usefulness they hold for approaching collaborative, consumer-directed, research. In this chapter I conclude by exploring a set of personal construct concepts that inform a coherent approach to



exploring consumers' experiences, in line with the values I endeavor to embody in this work. In Chapter 4, I review the literature on human change and transition. In Chapter 5, I describe qualitative research approaches, which form the basis of my methodological approach in the two studies, the connections between personal construct theory and these qualitative methods and theoretical and meta-theoretical perspectives. In Chapter 6, I describe the aim and research questions that guided my inquiry in the two studies presented.

In Chapter 7, a description of Study 1 is provided, with the results of the analysis presented in Chapter 8. In Study 1, I examine two sets of data gathered by Consumer Researchers (CRs) in focus groups and then interviews with consumers. I conducted Study 1 to examine and understand the experience of being a consumer of mental health services, as a basis for developing an understanding of what the experience of becoming a researcher involves for consumers. I explore the themes identified through Interpretative Phenomenological Analysis (Smith, Flowers & Osborn, 1997; Smith, Jarman & Osborn, 1999; Willig, 2001) of the transcripts of participants' experiences of using mental health services. Eight themes were identified and agreed on by the research team, from analysis of focus group data. These themes were used to form the basis of our interview questions. Ten themes emerged from analysis of the interview transcripts providing a rich and layered description of what it is like to use mental health services.

A discussion of these results, in connection to other literature about experiences using mental health services, and of recovery, is presented in Chapter 9. In this chapter I also explore the implications of the results from Study 1 in terms of consumer evaluation of mental health services, and mental health service policy and service provision. The results I found in Study 1 support other findings (eg: Brems, Johnson, Corey, Podunovich, & Burns, 2004) in identifying and highlighting areas of importance to consumers' sense of mental health and recovery that mental health services need to further develop.

Chapter 10 entails a description of Study 2. I conducted Study 2 to examine the experience of becoming a researcher for the consumers working on the CEO-MHS research team, and specifically sought to understand how the transition to consumer researcher was experienced: what emotions accompanied the transition they experienced and what changes to their self-construing occurred. To achieve this, I conducted a focus group and a series of interviews with the participants - my colleagues and co-researchers on the CEO-MHS team. In the focus group, I invited Consumer Researchers to consider the themes from Study 1 and talk about if and how these resonated with their experiences of becoming researchers, while working on the CEO-MHS project. I conducted two interviews with the CRs, during which, together, we explored their personal experiences of becoming a researcher. As in Study 1, I used Interpretative Phenomenological Analysis to interpret participants' accounts, and identify seven themes. I present the results of Study 2 in Chapter 11. The themes that emerged in Study 2 reveal the experience of becoming a researcher to be multifaceted and complex, accompanied by both positive and negative emotions, personal opportunities and challenges. The experience of becoming a researcher for mental health consumers appears to be similar to experiences of recovery, involving similar types of personal change, with relationships also playing a central role in their experience. A discussion of these results is provided in Chapter 12, in which I also examine how the results from Study 1 contribute to understanding the transition from consumer to consumer researcher.

In Chapter 13, I use my conceptual understanding, based in personal construct theory, to examine the experiences for mental health consumers of becoming evaluation researchers, drawing the two sets of results together. Here I present a model of the experiences for mental health consumers becoming evaluation researchers, which is grounded in the data from the two studies, and personal construct theory. In the final chapter, Chapter 14, I consider the overall findings of this body of work, examining the implications, and limitations of the research. The results of the research support the policy

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directions relating to consumer involvement in research, and support the recovery and work literature. As well, my findings highlight a number of directions mental health services should better explore to support consumers' recovery and empowerment.

## CHAPTER 2

### EVALUATION AND RESEARCH IN MENTAL HEALTH SERVICES: CURRENT PRACTICE AND THE ROLES OF CONSUMERS

In this chapter I will discuss the context from which the model of mental health consumers becoming evaluation researchers is being developed, and outline the roles consumer researchers have played in this context. To explore the background to the model development, the area of evaluation will be reviewed. I will firstly address the question of *why involve consumers in evaluation research?* I will then look at what is meant by evaluation, and what happens in mental health service evaluation currently. I will then examine whether what occurs in the mental health field fits a modern definition of evaluation. As part of this review, the issue of consumer involvement in evaluation is raised, and so leads me to review consumer participation in health services and research generally and then specifically to focus on consumer involvement in mental health services and research. I will conclude the chapter with a review of literature relating to consumers' experiences of becoming researchers.

### Context of the Model Development

This PhD research is situated within the context of the Consumer Evaluation of Mental Health Services (CEO-MHS) project, a three-year project funded by the Australian Research Council and Illawarra Health, a regional mental health service in NSW, Australia (Oades, Viney, Malins, Strang & Eman, 2005; Viney et al, 2004).

CEO-MHS is a collaborative project with the overall aim of developing a consumer driven and directed method of evaluation of mental health services (Strang et al, 2001), and could be described using Hunt's (1997) term of consumer health research. In her discussion of consumer health research, Hunt identifies the parameters of this style of research as "research conducted by and with consumers" as opposed to "research conducted on behalf of consumers" (1997, p. 48). Hunt's description of consumer health research is similar to what Faulkner and Nicholls (2003) call "User-led research" and closely parallels Viney's description of a mutual orientation model of conducting research, which is discussed later in this thesis (1987). A clear distinction drawn between

these approaches to research and others relates to who controls the research process. Hunt also notes that consumer health research is closely related to action research, with similar participatory and empowering principles driving it. In addition, Hunt suggests that one important aspect of consumer health research is its focus on finding and using appropriate “research methods to elicit information relevant to consumers” (1997, p. 49). The significance of consumer health research, or user-led research, is that it enables consumer health groups to shift from reactive to proactive stances, through the creation of a genuine consumer voice in research (Hunt, 1997; Faulkner & Nicholls (2003); Faulkner & Thomas, 2002). Hunt (1997), and others (Faulkner & Nicholls (2003); Faulkner & Thomas, 2002) discuss the creation of different knowledge out of this approach to research, which may stimulate new directions for research generally, because of its ability to capture the diversity and complexity of consumer perspectives. Because of this, a broader range of views may be introduced into debate about health and health care, and an opportunity to affect policy development is also created.

Another significant aspect of consumer health research is the educational opportunities it creates (Hunt, 1997). Specifically, educational opportunities are created for the consumers involved in the research process. It also offers the general community the opportunity to become educated about specific health issues. Hunt suggests that “consumer health research is significant for its influence on social action” (1997, p. 50).

Hunt notes issues of control and power, and the extent to which professionals are involved as dilemmas for consumer health research. She suggests that, while a number of collaborative solutions between professionals and consumers can be found, “a defining feature of consumer health research is a high level of consumer involvement.” (Hunt, 1997, p. 51). The relationship between members of a research team should not be of researcher and research subject. This issue of the nature of relationships within research groups, and between people involved in research is addressed further in the next chapter,

when I discuss personal construct theory as offering an alternative meta-theory to that of the medical model, and as the underlying meta-theoretical framework for this research.

The CEO-MHS Project has been conducted by a team of researchers consisting of:

1. a management committee comprising three academic members of university staff and two consumer representatives from local mental health services;
2. a Consumer Researcher team, originally comprised of 14 mental health consumers who had applied for the consumer researcher positions. By 2003, the final year of the CEO-MHS project, this team included nine active researchers;
3. research students, including myself; and
4. a Project Officer, who provided administrative and research support to the team.

In addition the team worked with three external consultants.

While the major aim of the CEO-MHS Project was to develop a consumer driven and directed method of evaluating mental health services, the team worked with a range of other objectives also. These aims were: to create a genuine research partnership between academic, university based researchers and consumer researchers; to empower consumers through acknowledgement of their expertise as the people who use, and indeed depend on, mental health services; and to demonstrate consumers' ability to conduct evaluative research in the mental health field. All of these aims were driven by the overarching aim of improving mental health services, through genuine evaluation by consumers.

It is from this context that the model of mental health consumers becoming evaluation researchers is being developed. As the review of the literature relating to consumers' experiences as researchers later in this chapter reveals, very little research has been conducted, exploring what it is like for consumers becoming researchers within the mental health field, or what the psychological processes involved in this transition are.

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### Consumer Researchers in the CEO-MHS Project

In 2001, 14 consumers from the local area were employed to work as research assistants, by the University of Wollongong, specifically on the CEO-MHS project in the role of consumer researchers. These positions had been advertised in local newspapers, as well as in Illawarra Health, Mental Health services. Selection criteria for these positions were identified by a committee comprised of the CEO-MHS Management Committee members, one of the external consultants to the project, several research students, including myself, and the acting mental health director of the local health service. The selection criteria included five essential, and one desirable criterion, which were as follows:

#### Essential:

1. Gained expertise from direct experience of mental/emotional distress and have used area mental health services.
2. Good communication skills
3. Good listening skills
4. Good translator into understandable language
5. Confidence to meet new people and willingness to undertake training in research skills.

#### Desirable:

1. An appreciation of the role of consumer participation in mental health service evaluation.

After completing an interview process and being offered a position within the research team, a three-day training session was held for all consumers employed (McLeod & Oades, 2001). It was during this training session that the team decided to adopt the name Consumer Researcher (CR), to describe the role they were taking.

As the assertion that the research fits within a consumer health research framework indicates, CRs were integrally involved in all aspects of the project:



additionally, as a team we also sought other consumers' views throughout the research process. The nature of the research components that CRs were involved in are outlined in Table 1, with each member of the team choosing from these areas the work they wanted to take part in for whatever reason – whether it be suitability of dates, preference for type of work, or any other reason. Therefore, each CR had a unique path of involvement in the research process; while some research activities are common to all, their experiences of becoming evaluation researchers reflect these unique patterns of involvement.

### Why Involve Consumers in Evaluation Research?

The brief review of the evaluation area I provide in this chapter demonstrates the central role evaluation can and should play in creating and maintaining good services, while the review of evaluation in mental health services reveals the challenges still facing this area. My answer to the question of *why involve consumers in evaluation research?* draws on the action research framework that underlies the research, which holds the position that knowledge is power. This is discussed further in Chapter 5 more specifically, but is also raised again in reviewing consumer participation and involvement in research later in this chapter. Involvement in research gives consumers knowledge, a power base from which to negotiate, and a forum which is recognised by services from which to act: evaluation research provides an opportunity to redress traditional power imbalances, giving consumers a voice at one of the critical fulcrums of decision making (Ochocka, Janzen & Nelson, 2002). Rapp, Shera and Kisthardt (1993) argue that not only should research amplify consumers' points of view, but that it is imperative that consumers be involved in framing the entire research process. They note that internationally, policy makers have established emphasis on consumer empowerment, however, that research conducted in mental health often does not reflect this empowerment agenda. They suggest that at times it may even be undermined in many ways (Rapp et al, 1993).

Table 1

*Stages of the CEO-MHS research project, and corresponding research tasks in which Consumer Researchers (CRs) engaged.*

Training	3-day training session and orientation, 2001 Further training in conducting interviews, 2002 Training in evaluation theory and methods, 2002/2003 Ongoing supervision and support, 2001-2003
Planning and designing research method	Development of Focus Group questions/guide, 2001 Development of Interview questions/guide, 2002 Making sampling decisions for interviews, 2002 Planning feedback sessions for participants, 2003
Conducting Data Collection	Facilitating Focus Groups with consumers of mental health services, 2001/2002 Conducting Interviews with consumers of mental health services, 2002/2003 Quantitative survey piloting with consumers of mental health services, 2003
Data interpretation/analysis	Interpretation and validation of meanings in Focus Group transcripts, and coding of data Interpretation and analysis of interview data.
Dissemination	The Mental Health Services conference presentation, 2002 The Mental Health Services conference presentation, 2003 Feedback presentations, to participants from focus groups and interviews, 2003 Writing journal article with team, 2003
Original work	Development of CEO-MHS Evaluation Framework, 2003 Development of CEO-MHS Questionnaire, 2003

Linhorst and Eckert (2002) provide seven reasons why consumers should be involved in evaluation of mental health services, on a continuum from philosophical to more practical, outcome oriented arguments. The seven reasons are:

1. it is consumers' right, as a major stakeholder;

2. involvement is an opportunity to ‘enrich and improve’ evaluation. Consumers have different perspectives and this differing perspective will add depth to an evaluation;
3. consumer involvement focuses on issues important to consumers;
4. inclusion is consistent with some models of treatment – eg: psychosocial rehabilitation promotes consumer involvement in all aspects of service;
5. involvement is consistent with numerous models of evaluation (noting specifically Participatory action research (PAR), empowerment evaluation, and utilization-focused evaluation, however suggest this is not exhaustive);
6. accrediting bodies require consumer involvement; and
7. participation benefits consumers.

Consistent with Linhorst and Eckert’s (2002) arguments, other researchers and policy makers have recognised the social justice of consumer involvement in evaluation and recognise the differing perspectives consumers bring to evaluation of services compared with mental health professionals and/or external evaluators (Deane, 1987; Gill, Pratt & Librera, 1998; NSW Health, 1999; Perkins, 2001; Rapp et al, 1993). Additionally, there is recognition, in Australia and overseas, that consumer participation should be linked to issues of quality and improvement in services (Australian Health Ministers, 2003; Consumer Focus Collaboration, 2000; Wadsworth & Epstein, 1996<sup>b</sup>; Wykes, 2003, & 2004). To completely frame an answer to this question then, after addressing the area of evaluation, I will review the literature and extent of consumer participation in services and research.

### What is Service Evaluation?

There are many definitions of “evaluation”, and different models of evaluation reflect differing definitions (Clarke, 2000; Mertens, 1994). Fifteen years ago, Guba and Lincoln (1989) asserted that the nature and meaning of evaluation has changed

dramatically over the last century. They outline development in views of evaluation, from evaluation as measurement, through evaluation as description, to evaluation as judgment of value or worth. Guba and Lincoln describe this development as additive, so that what they describe as the third generation of evaluation (judgment) also incorporates the definitions and purposes of earlier generations. They suggest that these three generations of evaluation did not extend far enough and raise a range of concerns with the definition, and meaning, of evaluation as proposed in these first three generations. They propose Fourth Generation Evaluation (1989) as an alternative. From Guba and Lincoln's analysis of the history of evaluation, however, we can determine that components of evaluation include measurement, description and judgment, but that necessary in addition is involvement of stakeholders, particularly those most at risk from the evaluation (1989).

Patton's broad definition of evaluation as "any effort to increase human effectiveness through systematic data-based enquiry" provides a useful position to continue framing an understanding of evaluation (1990, p. 11). Central to this definition is a focus on evaluation as attempting to affect positive change. This provides the imperative that evaluation goes beyond mere judgment of the value or worth of a program, and embodies a process of reflection and implementation. That is, to fit this definition of evaluation, results must be used (Robson, 1993).

An enduring, however contentious, issue is the political nature of evaluation. Shadish claims that "good evaluation responds to important social needs" (1994, p. 347). Wadsworth takes this stance further in asserting that: "evaluation is for those whose unmet needs provide the benchmark and driving values for checking whether a service, campaign or activity works." (1997, p. 2).

From this discussion then, evaluation can be summarised to include: measurement, or other systematic data collection; description; judgment; an attempt to create or implement change based on this judgment; and that evaluation in itself is a political activity.

Modern theories of evaluation include Guba and Lincoln's (1989) fourth generation of evaluation, Responsive Constructivist Evaluation, which is organised by stakeholders' claims, concerns and issues, and their process uses a constructivist methodology and meta-theoretical approach. The constructivist meta-theory underlying this theory of evaluation is consistent with that of personal construct theory, which will be described in detail in Chapter 3. Fetterman's Empowerment Evaluation (1996) is another contemporary theory of evaluation, and was developed specifically to help programme participants evaluate themselves and their programme, thus having a collaborative, participatory tone, and is based on Zimmerman's work on empowerment theory (Fetterman, 1996).

#### Evaluation in Mental Health Services: Contemporary Approaches

Consumer perspectives are becoming more widely recognised in service evaluation and planning, because, in great part, of the consumer movement (Campbell, 1997; Perkins, 2001; Ralston, Beesley & Bogue, 1998). Consumer participation in the evaluation of services is included in the National Standards for Mental Health Services in Australia (Australian Health Ministers, 1997), and internationally similar recommendations are made for inclusion of consumers in service planning and evaluation (Department of Health, 1999;<sup>a & b</sup> US Department of Health and Human Services, 2001).

Traditionally, methods of evaluating mental health services have been driven by professionals' perspectives (Campbell, 1997; Prince & Prince, 2001) despite marked differences noted between these and consumers' constructs about what is desirable and/or effective (Gill et al, 1998; Perkins, 2001). Perkins (2001, p. 9) poses the question, where should the criteria for an evaluation of mental health services come from: "Whose views of effectiveness are paramount and who has the right to define what service users need?"

Milne (1987) describes the different types of mental health program evaluation as: effort; outcome; process; efficiency; or client satisfaction. Coursey (1977) offers a similar

overview of models of program evaluation for mental health services, defining seven approaches: outcome, goal attainment, systems analysis, cost analytic models, descriptive and quality assurance approaches, program planning and management-based methodologies, and the legal approach. The framework for evaluation outlined by the Australian Commonwealth Department of Health and Aged Care (2001<sup>a</sup>) is in many ways consistent with more modern definitions of evaluation particularly in its cyclical orientation and inclusion of acting on evaluation findings as part of the evaluation process. The discussion in this document is still limited, however, in terms of consumers' roles in evaluation, or in advocating a consumer-directed evaluation process.

#### The Reign of the Consumer Satisfaction Survey: Exploring the Limitations of this Approach as a Method of Evaluation

It is evident from the scope of the categories outlined above that the history of evaluation in mental health services has typically reflected little in the way of genuine consumer input. From Milne's categories, consumer satisfaction surveys are the only class that *must* involve consumers of services directly. As Clarke (2000) notes, "largely as a result of the emergence of quality assurance mechanisms, consumer satisfaction surveys have almost become a routine feature of the information gathering systems of many public sector organisations involved in providing a range of health care and social welfare services." (p. 15). Consumer satisfaction surveys have been a popular method of service evaluation in mental health (Edlund, Young, Kung, Sherbourne & Wells, 2003; Williams, Coyle & Healy, 1998; Williams & Wilkinson, 1995), however, numerous studies have criticised both the underpinning concept of satisfaction, as well as methodological aspects of these surveys. The criticisms and limitations, discussed in detail below, revolve around these main issues:

- consistently high levels of satisfaction are found using consumer satisfaction surveys, which is not a situation reflected by the consumer literature (Clark, Scott, Boydell & Goering, 1999; Williams, 1994);
- different levels of satisfaction are found when a global measure of satisfaction is compared to semi-structured interviews with the same consumers (Lovell, 1995);
- satisfaction surveys have traditionally been developed by professionals, not consumers (Campbell, 1997; Hansburg et al, 1996; Lovell, 1995; Perkins, 2001);
- differences are found between responses on satisfaction surveys depending on the role of the person administering the survey (Clark et al, 1999; Gill et al, 1998; Hansburg et al, 1996; Polowczyk, Brutus, Orvieto, Vidal & Cipriani, 1993).

Avis, Bond and Arthur (1997) examined the model of patient satisfaction that presumes that patients judge their level of satisfaction by comparing their experience of care with their prior expectations. In doing this they examined common themes in patients' evaluations over time experiencing care. To do this, patients were interviewed immediately before and after initial consultations and sub-samples were followed up to observe changes in their perceptions of the care they had received.

Avis et al's (1997) findings raise some problems for the consumer model of satisfaction. They suggest that satisfaction may be too simplistic to accommodate patients' responses to their experiences of care and that questionnaires based on the assumption that patients judge their satisfaction by comparing their care with a set of ideal positive expectations may be creating the "satisfaction" of such expectations as an artifact. Additionally, the authors indicate that their findings suggest that satisfaction may be a response to psycho-social aspects of the encounter, rather than a result of expectation fulfillment. Therefore, it may be inappropriate to conclude that reported satisfaction corresponds to expectation fulfillment.

In this study, Avis et al (1997) found that patients evaluated the services they received in different ways over time, and contact, with the care experience. Therefore,

they suggest there is a risk of taking these changing views out of context by asking patients to make judgments about their satisfaction with discrete episodes of care, when for most each episode is only part of a series of care interactions.

Given these findings, Avis et al (1997) suggest that while satisfaction may appear to be a relevant outcome of a specific encounter, it can seem inadequate in the context of the story of treatment or care, concluding that serious limitations remain with the consumer model of patient satisfaction. They suggest qualitative approaches to patient evaluation of services as a practical way to overcome these limitations. The process of evaluation through patients' stories provides potentially valuable information about the functioning of health care services, and unlike satisfaction surveys does not run the risk of channeling patients' concerns into avenues defined by anyone other than the patient.

Williams and Wilkinson (1995) similarly argue that the concept of satisfaction is insufficient, and too general to provide a meaningful guide to the way consumers think about services. They discuss a range of difficulties with the implicit assumption that consumers carry expectations, underlying the construct of satisfaction, arguing that “expectation plays a part in patient’s evaluations of care, but at best the relationship is complex, and at worst, fulfillment of expectations may have little to do with expressed satisfaction.” (p. 561). Like Avis et al, Williams and Wilkinson (1995) advocate that more qualitative methods are necessary to gain genuine understanding of consumers’ beliefs about, and evaluations of, services. Swain-Campbell, Surgenor and Snell (2001) provide evidence that more qualitative approaches in questionnaire format (that is, open-ended questions) can successfully identify areas consumers’ believe need improvement that more structured formats do not. This supports the push made by authors like Avis et al (1997) and Williams and Wilkinson (1995) to use more qualitative methods in eliciting consumers’ evaluations of services.

In support of these criticisms, Lovell (1995) found conflicting results in reported satisfaction when using both a global satisfaction scale, and semi structured interviews



with the same consumers. The satisfaction scale results indicated high satisfaction; however, important areas of dissatisfaction were identified in the interviews.

Campbell (1997) and Lovell (1995) suggest that satisfaction surveys developed by professionals, have limited value from consumers' perspectives. Campbell notes that professionally developed satisfaction instruments, rather than measuring those issues shown to be of concern in consumer literature, tend to measure issues that mental health staff consider important. This author highlights a divergence between areas of concern to professionals and consumers. She also suggests a reluctance to ask questions that will capture consumer dissatisfaction in traditional satisfaction surveys. Similarly, Perkins (2001) highlights the issue of difference between mental health professionals and mental health consumers' views about the desirability of different outcomes. As Perkins notes, this divergence indicates that for any measure to adequately reflect consumers' concerns, it must be developed from a consumer base. Research exploring the extent and nature of agreement between consumers, their providers and their family members on outcome and service priorities also indicates low levels agreement between these stakeholders (Fischer, Shumway & Owen, 2002). Fischer et al's (2002) research further indicates that providers in their study had little awareness of consumers' preferences.

Hansburg et al (1996), recognising that the elements of satisfaction in surveys are typically identified by professionals rather than consumers, developed a survey about screening services based on consumers' views identified in a focus group. Hansburg et al (1996) found consumers' levels of satisfaction using this tool to be lower than those reported in other studies. While the repetitively high levels of satisfaction found using traditional surveys has caused questioning of the instruments (Clark, Scott, Boydell & Goering, 1999; Hansburg et al, 1996; Williams, 1994) these results further demonstrate the inadequacy of the traditional, professionally developed tools.

In attempting to address this difference, Hansburg et al (1996) cite the nature of the service in which consumers were recruited for the study as one possible factor,

suggesting that this setting may have been particularly distressing for consumers. They also suggest that having consumers administer the survey to other consumers may have led participants to feel freer in expressing dissatisfaction. Other research supports this latter suggestion, however even when consumers have administered other, more traditional surveys which are developed without consumer input, satisfaction is still typically higher than anecdotal evidence suggests (Clark, et al, 1999). It seems likely, then, that contributing to the finding of lower satisfaction reported in this study is use of an instrument focusing on issues relevant to consumers.

To explore some of the limitations mentioned above, Clark et al (1999) conducted a study to compare the effects of staff versus consumers collecting data on consumer satisfaction with services. The findings of this study were that high levels of satisfaction were reported regardless of the interviewer, although a significantly greater number of extremely negative responses were given when consumers were interviewers. Clark et al (1999) observe that while one explanation may be that consumers were satisfied with the services received, they cite factors such as hesitancy to disclose due to feelings of dependence on the system, social desirability, and invalid instruments and data collection methods as possible limitations to this conclusion. Clark et al (1999) comment that 78% of the consumers interviewed in this study were regarded as frequent users of the services, and note that possibly dissatisfied consumers have already left the program, therefore not being sampled in this study. Their findings also indicate the possibility of an interviewer effect when a consumer is dissatisfied with an aspect of the service. The importance of opportunities for consumers to be able to address issues with other consumers in privacy is an important measure towards valid feedback from consumers of the services.

Polowczyk et al (1993) completed a study similarly exploring differences between staff and consumer administration of satisfaction surveys. Again, high levels of

satisfaction were found across the groups, however those surveyed by consumers reported significantly less satisfaction.

Gill et al (1998) administered two satisfaction measures, the CSQ and MSS over seven programs to determine whether using consumer surveyors would eliminate or reduce the response bias found toward staff administration. The findings of this research were more complex. While in four of the programs, staff administration biased scores upward as expected, in two programs, satisfaction scores were elevated when consumers administered the surveys. Gill et al (1998) suggest that factors such as social desirability and ingratiation may at times be relevant in the relationship between consumers, as well as between consumers and staff. It seems that in traditional settings, in which consumers are empowered with few roles in the operation and governance of the service, staff administration will increase satisfaction scores. These findings indicate that the direction of the bias is more unpredictable than previously considered.

Williams et al (1998) found through conducting a series of interviews with consumers to explore their experiences with services, and their responses on a satisfaction survey, that satisfaction surveys do not produce results that directly relate to consumers' experiences of services. This research supports the concerns raised by Avis et al (1997) and Williams and Wilkinson (1995) regarding the conceptual basis of satisfaction. Williams et al (1998) argue that if the purpose of a satisfaction survey is to provide consumers' with a means to contribute to service development and change, these surveys are not actually suited to this purpose. What they have found indicates that high satisfaction does not indicate that consumers' have had positive experiences with services, but rather, "more often reflect attitudes such as 'they are doing the best they can' or 'well, it's not really their job to do...'". (p. 1358).

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### Do Satisfaction Surveys fit a Current Definition of Evaluation?

The literature reviewed above indicates a range of methodological and theoretical limitations to the use of satisfaction surveys, and raises questions regarding the applicability of this method to generating organisational change. Another test of the usefulness of satisfaction surveys is to consider whether these instruments fit a modern definition of evaluation, as described earlier in this chapter.

Evidence of application of modern evaluation theory to mental health evaluation is quite limited. Exceptions to the norm will be discussed in the following section. Kirkhart and Morgan (1986) suggest while a considerable amount of evaluation research in mental health has been conducted, it has been typified by a gap between theory and practice. They note that in mental health research, evaluations have frequently lacked grounding in a conceptual model, while conversely conceptual models have been proposed with no link to empirical evidence.

The five evaluation categories that Milne (1987) outlined, identified earlier, correspond most closely to either first or second generation evaluation as conceptualised by Guba and Lincoln (1989). None of these categories alone fits a contemporary definition of evaluation. Milne highlighted the tendency in mental health service evaluation to replace the use of comprehensive conceptual models with a fragmented use of evaluation methods. He saw evaluative activity occurring, such as administration of satisfaction surveys, but not evaluation which involves a fuller process of change. The use of tools, like satisfaction surveys, which ultimately do not indicate areas within services that need change, because of the limitations described above, are not inherently useful to evaluation. Williams et al (1998) argue that satisfaction surveys do not help create more person-centred services, despite this being the impetus that lead to widespread use of these instruments. In their study, Williams et al (1998) found that satisfaction surveys do not generate information about consumers' experiences of the services; rather responses

reflect consumers' perceptions of services' duty and culpability. A modern definition of evaluation requires that evaluation be focused on creating change (in this case organisational change), and that results must be used. For results to be used, they must provide helpful information.

Satisfaction surveys used alone do not meet a contemporary definition of evaluation, and so while could be considered part of evaluative practice, do not constitute an evaluation on their own. What is missing is articulation of the processes around how these tools should be used: how the results feed into quality improvement cycles within services, being acted upon to create genuine change. While surveys are being used to simply demonstrate that a suitable percentage of consumers of a service are satisfied, they are not genuinely contributing to modern evaluation, rather fitting a first generation definition of evaluation as measurement. Ingram and Chung (1997) argue that satisfaction measures are too often used primarily to assist marketing and accountability processes, which leads to focus on positive aspects. They argue that if satisfaction surveys were used by services to more genuinely assist quality improvement processes, any dissatisfaction would become the foci (Ingram & Chung, 1997).

Other criticisms are leveled at the tools typically employed in mental health service evaluation. For example, Rapp et al (1993) note: "most current instruments are not suitable because they do not reflect an empowerment perspective" (p. 732). They argue that it is essential for new instruments to be developed, and that this development must occur through collaborative effort between consumers and professional researchers. These processes ensure relevance to consumers in terms of both language used and areas of importance measured. Similarly, Williams et al (1998) also suggest that instruments that access consumers' experiences of services, and the meanings and values attached need to be developed, and that these instruments need to articulate with service improvement and development processes.

The CEO-MHS project aimed to fill this gap identified, by developing a tool, derived from consumers' experiences, which is situated within a comprehensive, consumer directed, evaluation framework. This evaluation framework needs to be reflective of a modern definition of evaluation.

### Alternatives for Mental Health Service Evaluation

Despite the criticisms above, some excellent contemporary examples can be found in the literature, in which models of evaluation for mental health services have developed, with strong consumer leadership. They include the Understanding and Involvement Project (Wadsworth & Epstein, 1994, 1996<sup>a & b</sup>), User Focused Monitoring (UFM) (Rose, 2001) and the evaluation of Laurel House described by Boll (1995).

The Understanding and Involvement Project was a ground breaking consumer-driven action research project conducted by the Victorian Mental Illness Awareness Council Inc. over a period of three years from 1993 to 1996 (Wadsworth & Epstein, 1994, 1996<sup>a & b</sup>). Fundamental to the project was the belief that “consumers have important insights, understandings and assessments of their experiences essential to point services in the direction of improved quality” (Wadsworth & Epstein, 1996<sup>b</sup>, p. 10).

A comprehensive model to seeking consumers' evaluative feedback was developed as one outcome of the project, which strongly advocated a performance management approach versus performance monitoring or measurement. The model emerged from action research conducted within an acute psychiatric unit, thus is embedded within practice. The model involves twelve aspects, described in the final project report (Wadsworth & Epstein, 1996<sup>b</sup>) as:

1. a quality assurance/ quality improvement framework;
2. not just consumer feedback, but also staff-consumer communication;
3. comprehensive and systematic;
4. robust and “built-in”;

5. achieving culture shift, supporting culture carriers and building critical mass;
6. multiple consumer feedback methods or “mechanisms”;
7. three sites: feedback and communication in decision making sites; nurturing feedback in consumer-only sites; and feedback and communication in decision free sites;
8. at all levels of all relevant organisations;
9. centred on the acute unit and other high-risk settings;
10. consumers as staff;
11. consumer support resources and infrastructure; and
12. consumer-driven and staff collaborative.

Another example is User Focused Monitoring (UFM) developed in the UK at the Sainsbury Centre for Mental Health (Rose, 2001). UFM provides a model and method to evaluate mental health provision from the perspectives of consumers, and is based on principles of being “user-focused” and locally grounded. Rose (2001) describes in clear detail the initial stages of an evaluation conducted using UFM: the process begins with the groundwork of development of a local group of consumers to conduct the UFM. This team then plays the central roles of developing a locally relevant approach to getting feedback from consumers about their experiences and perceptions of the services. Data collection approaches include a questionnaire, site-visits, and focus groups. Rose (2001) explains that a core set of questions were developed during the first UFM process that have been adopted by all the projects reported by Rose (2001). UFM team members concurrently receive training in the skills of interviewing, conducting site-visits and facilitating focus groups. The report by Rose presents results from UFM projects in eight sites in England. While overall, the report does not elaborate specifically on the evaluation process beyond describing the initial aspects of the process described above, Rose does report the UFM was conducted in one site on two occasions, approximately

two years apart, and a targeted feedback strategy adopted to encourage change. Feedback was provided to the project advisory group which included the health authority and managers, frontline staff and consumers, and community mental health teams. Rose reports that changes occurred in responses to the UFM during the second round of data collection, in the areas that received targeted feedback.

Boll (1995) discusses a self evaluation conducted by Laurel House, a psychosocial clubhouse in Stamford, Connecticut. He states:

The self-evaluation was guided throughout by the idea that members could make a significant contribution to the evaluation effort. Organisational theorists point to the value of empowering front line workers with responsibility for monitoring their own productivity and quality control ...At Laurel House, this idea was applied to the members of the clubhouse as well as program staff. (Boll, 1995, p. 80).

The Steps of the Laurel House evaluation Boll describes are:

1. Development of an evaluation protocol. A committee of three members and two staff developed a list of questions pertaining to clubhouse activity. Since the purpose was to initiate a process of self-examination, Boll (1995) states, the questions were deliberately open-ended.
2. Over three months staff and members held weekly discussion regarding the operation and processes of the clubhouse, and at the end of the three months, each unit produced a report summarising its findings, and highlighting proposals for improving operations and addressing weaknesses identified.
3. The third step involved visits by an evaluation team, consisting of one internal and one external evaluator. This evaluation team firstly observed the unit, participating in regular activities. The evaluation team also met with staff and clubhouse members. At the completion of these visits and meetings, the team collectively



discussed their assessments, and developed a list of recommendations for the unit, which were reported back to the clubhouse membership in a meeting.

4. At this stage, each unit had a list of goals and objectives to guide the next 12-months. A schedule of quarterly meetings for the clubhouse was established, to monitor the progress of each unit towards its goals, and to provide an opportunity for goal modification and feedback.
5. Over the 12-months, Boll describes that the clubhouse was also involved in a series of other activities, such as member and staff opinion surveys.

Other examples of methods for mental health service evaluation are found in the literature, which involve consumers in development of surveys. These examples include development of the Carers' and Users' Expectations of Services – User Version (CUES-U) (Lelliot et al, 2001). The CUES-U instrument was developed specifically to address the issue that instruments found to be available to measure consumers' experiences of services did not “address all or even most of the issues that are important to service users.” (Lelliot et al, 2001, p. 67). Data from focus groups and seven in-depth interviews with consumers were used to identify domains of importance to consumers as the basis of the instrument development (Lelliot et al, 2001).

While these examples exist, the limitation is that the evaluation models proposed are either not clearly articulated in terms of their theoretical positions, often, like UFM do not clearly describe full evaluation processes, and/or are not easily replicable. A clear framework that describes a full evaluation process, with well articulated theoretical and empirical grounding and that is readily applicable to a working mental health service is required. This is what the CEO-MHS project aimed to develop.

### Consumer Participation in Health Services and Health Research

Hunt argues that, despite growing discussion and awareness of participatory action research styles in health, there is evidence that in Australia a “non-participatory,

biomedical research model remains a dominant paradigm” (1997; p. 49). Goodare and Smith (1995) suggest that consumers: “should help to decide which research is conducted, help to plan the research and interpret the data, and hear the results before anyone else” (p. 1277). They state that these are consumers’ rights in research, as they (the health consumers) are central to the purpose and conduct of any health research. Goodare and Smith argue that consumers are in a unique position to ensure research that is conducted is relevant, and conducted appropriately, and ethically.

Goodare and Lockwood (1999) discuss the traditional involvement of consumers in health research as “subjects”, at times “objects”, but not colleagues. They suggest that consumers have the experiences and skills that complement those of researchers. Having had experiences of living with a particular health problem/diagnosis and using services, they will have insight into what research questions are useful and how these should be framed. This position is supported by Liberati (1997) who maintains that the relevance and quality of much health research falls short of consumers’ needs.

While authors recognise that some progress (and some clear exceptions) in consumer involvement in health research has occurred generally (Goodare & Lockwood, 1999; Oliver, 1995; Liberati, 1997), there is still much to be achieved in making this a genuine change. There are many challenges facing attempts to collaborate, particularly relating to funding, and the dual roles consumers have, which professionals do not. Consumers often have other jobs, whereas academics can focus solely on the research at hand (Goodare & Lockwood, 1999). Liberati (1997) touches on the power imbalance which underlies the disparity between rhetoric and practice in this area, suggesting that relevant stakeholders’ views are not considered equally, commenting that “even among progressive scientists and health care professionals, a paternalistic attitude still prevails” and beliefs that consumers lack the knowledge and skills to participate dominate. While there is clearly still much to be achieved in the area of genuine consumer participation in health research, policies in Australia (NHMRC & Consumers’ Health Forum, 2001) and

in the UK (Department of Health, London, 1999<sup>a</sup>, 2000) reflect a growing commitment to enactment of consumer participation at general health levels.

### Consumer Participation in Mental Health Services and Research

Within the mental health field, involvement of consumers in services and research faces not only the challenges evident within most health research (Hunt, 1997; Goodare & Lockwood, 1999; Liberati, 1997), but also unique challenges relating to how people diagnosed with mental illnesses are viewed, an implication of the dominant modes of thinking on which mental health services are based (Campbell, 2001). I will discuss these issues in greater detail in the next chapter. As I have outlined above, Liberati (1997) notes that a challenge for involvement of consumers of general health services in research is the “paternalistic attitude” amongst professionals that “still prevails”, flowing from which are beliefs that consumers lack any skills and knowledge which would make their participation valuable. I suggest that this paternalistic attitude is stronger within the mental health field, and is probably a major factor contributing to Byas et al (2002, p. 75) recently concluding that: “it has been a rare phenomenon for consumers to be actively involved in mental health research and evaluation beyond the role of research subject.” Hansen, Hatling, Lidal and Rudd’s findings support this: these authors suggest that mental health professionals appear to “still be unwilling to trust and respect the patient view.” (2004, p. 296). Rose (2003) as well as Telford and Faulkner (2004) also draw similar conclusions.

Crawford (2001) suggests that while previously, discussion focused on whether consumers should be involved in service development and planning, we are now at a stage at which this discussion is redundant. Rather, he suggests discussion should now be focusing on how consumer involvement can best be achieved. Indeed, as Crawford, and many others note, at national and international levels, recognition of consumers’ valuable role in determining optimal care, and shaping effective services has been established

(Australian Health Ministers, 2003, 1997; Department of Health, London, 1999<sup>a & b</sup>; US Department of Health and Human Services, 2001). Internationally, mental health policies reflect this acknowledgement of the importance of consumer participation in all levels of service planning and provision.

Simpson and House (2002) observed, however, that despite government and policy commitment to involving consumers in delivery and evaluation of services, the effects of this has not been rigorously assessed. They reviewed comparative studies to assess the effect consumer involvement may have, and note that there is a difference between non-consumers and consumers in the three areas of literature they reviewed. Their review substantiates the idea that consumers with varying histories can be involved, and that while there were no detrimental effects of involving consumers in any of the studies they reviewed, there was consistent suggestion that this may be beneficial to both consumers currently using services, and to the services themselves. These commentators emphasise the importance of providing appropriate support, both practical and personal to consumers, highlighted by the studies they reviewed.

The enactment of policy regarding consumer participation within Australian mental health services remains limited with a range of barriers yet to be seriously addressed (Stacey & Herron, 2002). Stacey and Herron (2002) suggest that the remaining barriers include:

1. the discounting of consumer views based on a concept that consumers' are too diverse and so a collective view is impossible;
2. limited resourcing of consumer participation;
3. tokenism; and
4. an assumption that consumers' views reflect psychopathology by professionals.

They argue that ongoing structural and cultural change is still needed for these barriers to be addressed and for consumer participation policy to be fully enacted (Stacey & Herron, 2002).

Lammers and Happell (2003) conducted a series of qualitative interviews with fifteen consumers, to explore and discuss what opportunities they judged to be available for participation in the development, delivery and evaluation of mental health services. They note, in their review, that despite participation having been found to have positive outcomes for consumers, barriers still exist to effective implementation of participation. This finding has been supported by other studies in this area (Tobin, Chen & Leathley, 2002). They suggest that these barriers primarily relate to reluctance of service providers at individual and system levels. Results from their interviews highlight: the diversity of consumers, and varying levels of interest and ability possessed by consumers; the imperative that consumers are provided with opportunity to participate in all levels of service; that opportunity should be individualised according to needs and attributes of consumers; while for some consumers partnerships and participation worked, most identified many barriers still existing to their participation. The attitudes of service professionals were viewed as one major barrier.

Ochocka, Janzen and Nelson (2002) discuss the power differential between consumers and professionals, and the limitation this creates to genuine consumer involvement and participation in mental health service provision and planning. They suggest that one strategy for shifting this power imbalance is consumer involvement in research, citing the pivotal aspect of power over knowledge and resources in the relationship between consumers and the services they use. While Ochocka et al (2002) discuss several examples of consumer involvement in research, they note that: “understanding the implications of having consumer/survivors fully involved in a research process are still very limited” (p. 380). They suggest that understanding is particularly limited regarding how to create an inclusive environment where power is shared between consumers and researchers. They go on to discuss their own research, describing the: “value-driven strategies that were successful in reducing power differences between professional and consumer/survivor researchers” (p. 380) adopted.

These guiding values were: empowerment, social support, “learning as we go” and social justice. It appears that research perspectives that differ from a positivist, medical model approach are necessary if consumer involvement is to genuinely occur. I will explore in more depth the implications of the medical model on research in mental health and alternatives to this framework in the next chapter.

### Exploring the Experiences of Mental Health Consumers as Researchers

Because consumer involvement beyond that of “research subject” is so new to the mental health field, there are only limited examples of research in which consumers are involved as researchers (Henry et al, 2002; Howard, & El-Mallakh, 2001; Ramon, 2001; Rose, 2003; Telford & Faulkner, 2004; Trivedi & Wykes, 2002). Despite this limitation, Kaufmann articulated a range of roles possible for mental health consumers in research, during the early 1990s (Kaufmann, 1993). Kaufmann suggested six roles, on a continuum from the role of subject through to researcher. A set of different rights and duties define each role.

Even more limited, however, is discussion within this literature of what the experience of being or becoming a researcher is like for consumers involved. For example, Trivedi and Wykes (2002) identify the lack of information available in published literature about how involvement of consumers as researchers works, and their account of collaborating with consumer researchers attempts to address this gap by outlining the practical and conceptual steps, as well as the challenges they faced in their research partnership. Similarly, Howard and El-Mallakh (2001) discuss in detail the research process they engaged in, how consumer researchers were trained, and the efforts to maintain trustworthiness in data collection. Missing from these reports are consumers’ voices and experiences, and any account of what becoming a researcher meant to the consumers involved.

Two examples in which the experiences of mental health consumers working as researchers are examined and discussed are provided by Reeve, Cornell, D'Costa, Janzen and Ochocka (2002) and Morrell-Bellai and Boydell (1994). Both of these examples are from Canada. A further example is the work reported by Henry et al (2002) in the United States. I will review these examples in some detail.

Reeve et al (2002) discuss the experiences of three consumer researchers (CRs) employed on a project titled: 'Shifting the paradigm in community mental health: A community study of Implementation and Change'. This project extended over two and a half years, with an overall purpose to understand changes within three local community mental health organisations, which were striving to implement an emerging paradigm emphasising stakeholder participation and empowerment. In their paper, the CRs discuss a broad range of issues related to their experiences, from their expectations entering the project to how they contributed personally to the research findings and processes. Twelve threads common to the accounts of these CRs are: the importance of time for building trust and testing relationships; the challenge of facing 'self as consumer'; gaining skills; that they built confidence in their own ability; that a team approach is useful; being involved gave them an experience of being heard and respected, valued; creation of environment that allowed "me to be me"; empathy when they struggled; the challenge of maintaining "objectivity" during interviews; role reversals – when interviewing professionals; technical challenges; being involved helped with personal recovery; and developing new meanings and beliefs.

Morrell-Bellai and Boydell (1994) examined the experiences of six mental health consumers involved as paid researchers, working on various projects under differing conditions ranging from being employed to complete specific research tasks, to involvement in the entire research process. Morrell-Bellai and Boydell were interested in what the benefits of being involved in research were, if any, for the participants, as well as identifying what special needs may arise for consumers being employed as researchers.

They conducted semi-structured interviews with the consumers to address these questions. Their analysis leaves the question of what the experience of becoming a researcher is like unanswered, although their discussion indicates some areas that may be important: relationships within the research team and a sense of being supported; confidence and the link training plays in this. Their analysis indicates that benefits for the consumers interviewed related to a sense of greater self-esteem, and they reported feeling their experiences in research had been educative.

Henry et al (2002) describe employment of consumers as research assistants (RA) in a university-based mental health research centre at the University of Massachusetts in the United States. Their report describes how the RA positions developed, employee characteristics, job characteristics and responsibilities, the orientation and training provided, as well as supports and workplace accommodations that were necessary in their experience, and “boundary” issues encountered. A small component of the report is dedicated to describing the rewards and challenges of the research roles, from the perspective of the consumers who filled them. The positions described by Henry et al (2002) were 12 part-time RA positions. Eight of these were developed using a transitional employment approach, the other four used a supported employment approach. Henry et al (2002) describe one of the critical differences between these approaches as permanency of the position. The transitional employment places are time-limited, while supported employment positions are filled on a more permanent basis. According to Henry et al (2002), 22 consumers have filled these positions since the inception of the first 4 RA positions in 1997. In outlining the rewards and challenges of the job, Henry et al (2002) report on data collected with RAs at the time of job termination, in the form of self-administered exit questionnaires. These authors report that positive aspects of the job identified by RAs included: the opportunity to use or gain skills; the sense of mastery and confidence gained through the work; the variety in the work; reciprocal relationships RAs developed with peers and supervisors; a sense of empowerment felt at work; and a sense



of self-respect derived from work in the research setting. The negative aspects of the job highlighted in this report include: the lack of predictability in work and changing nature of tasks. These aspects of the job were linked to feelings of stress for RAs.

Several other sources provide some insight into the experiences of consumers as researchers. In the report by Rose (2001) describing User Focused Monitoring, a chapter is dedicated to accounts of the experience of UFM written by consumers from the UFM teams. Fifteen accounts are provided, and while many provide a sequential account of UFM itself, most provide some information about the personal experience of the researcher as well. The UFM researchers spoke of feeling uncertainty and apprehension, particularly when first becoming involved in UFM, and on conducting their first interviews. They spoke of finding the interview situations both inspirational and sad; as well, challenging and tiring. One mentioned how the interviews at times brought up painful memories from their own past. Overall, the results of being involved in UFM appeared to be reported as positive. The researchers spoke about greater confidence and growing courage, feeling satisfied and rewarded when they completed the UFM. One researcher said they felt they had done things they previously thought they never would. One researcher spoke about being shown, by her involvement, that she is “a capable person” as opposed to the “useless waste of space” she felt before (Rose, 2001, p. 26). Another researcher spoke of a sense of disappointment, however, that the UFM experience had not lead to permanent work.

The second alternative source of information about the experiences of consumers as researchers comes from the “Researchers Self-Reflections” in the final report of the Understanding and Involvement Project (U&I) (Wadsworth & Epstein, 1996<sup>b</sup>). Epstein worked several days a week as a researcher throughout the U&I project, and reflected: “the project has ...been an essential nourishing factor in my own metamorphosis back into worthwhile life.” (p. 193). Epstein writes of the role her work as a researcher on the U&I project played in “doing something”, but also the multiple challenges she faced

personally and professionally over the course of the three years. Epstein also describes the immense validation she found for her own meanings, finding confirmation for the sense she had made of her past experiences talking to other consumers through the project. Other consumers who worked as researchers on the U&I project reflected on their confusion, and questioning of self that occurred in the very early stages of becoming involved. This same researcher indicates the emotional journey being a researcher can entail: "I feel one moment totally in despair and another moment fully involved and a worthwhile contributor" (p. 197). Another wrote about experiencing relief as he came to a realisation of community, understanding that he is not alone in his suffering.

Allam et al (2004) describe collaboration between university researchers from Sheffield University in the UK, with consumers and carers from Lincolnshire Partnership Trust Service User and Carer Reference Group to evaluate a local assertive outreach centre. The consumers and carers in this team were involved in all aspects of the research project. The final section of their article is dedicated to reflections by team members, and consumers and carers report here that while taking part was hard work, it also held a number of benefits for them, including: a sense of being valued and listened to; new skills; development of closer working relationships within consumer and carer reference group; understanding of researcher roles; further understanding of consumer and carer issues; and the opportunities to disseminate findings to wider audiences. Allam and others also discuss some of the other key issues that arose during their collaboration. These included highlighting the need for consumer and carer researchers to be supported, and they also discuss the possible stress researching within services can create for consumers and carers.

Finally, Ramon (2001) also describes collaborative research between university researchers and consumers in the UK. Ramon discusses six key lessons the research team involved learned. These lessons included the centrality of supporting consumer researchers, and that while support should take a number of forms, Ramon suggests that

support should come from a key person, and be accessible and grounded in consumers' reality to achieve personal continuity. Ramon also notes the importance of collective support as an important feature of support. Ramon states that for consumers, participation in the research projects addressed issues of social inclusion and exclusion, and held important financial and personal rewards. Additionally, Ramon explores consumers co-researching as a way of addressing power issues. Ramon also discusses the relationships between university researchers and consumer researchers, and describes some of the complexities faced in terms of clashes of priority between these groups on occasion, and the difficulty of negotiating through the process with and without the formal language of research. Finally, Ramon also raises the practical considerations that are necessary to effectively engage in collaboration, such as ensuring adequate funding for the research and remuneration of consumers in the team, and the limitations and tensions faced for consumers on government benefits. As well, Ramon highlights the need for a comfortable, safe venue that can be accessed regularly.

In addition to these examples, literature exploring mental health consumers' experiences of work more generally is relevant to developing a model of them becoming researchers, as one of the fundamental aspects of this is its work role. While there is a larger body of literature available discussing work for consumers of mental health services, Schneider (1998) notes, however, that in general, the non-economic outcomes linked to work for consumers have yet to be fully explored.

Strong (1997) has used an ethnographic approach to examine what makes work meaningful for people with persistent mental illness, also exploring how this meaningfulness relates to recovery. Strong found that the experience of work held complex, varying meanings for consumers. Four overlapping and interacting themes that framed the meaning of work were: living with a label; becoming a capable person with a future; getting on with life; and finding a place in this world. Strong notes that an important implication of her study is that consumers: "emphasised issues related to

recovery and disabling environments rather than community reintegration or hospital recidivism.” (p. 37). Kirsh has also conducted studies to examine the meaning of work and important elements of workplaces as perceived by mental health consumers (2000) and to explore factors which facilitate workplace reintegration as perceived by consumers (1996). Similar to Strong’s findings, Kirsh reports themes relating to the meaningfulness of work in terms of contributing to society, being challenged and achieving (Kirsh, 2000), and that emphasise wholistic approaches (Kirsh, 1996) and the importance of the work environment (2000; 1996). Further exploration of the links between work and recovery has been reported by Provencher, Gregg, Mead and Mueser (2002) who have argued, based on findings from semi-structured interviews with 14 working and non-working consumers, that work is perceived by consumers as a means of self-empowerment, as well, perceived as promoting a sense of self-actualisation. These authors argue that work is closely linked to the experience of recovery.

A specific area of work that possibly holds much in common with that of becoming a researcher in the mental health field, is consumers’ experiences of becoming mental health professionals. Paulson (1991) highlights issues related to reliving the past, and whether or not consumers want their experiences recognised in their new roles. Mowbray, Moxley and Collins (1998) describe the personal benefits identified by consumers who worked as peer support specialists in mental health settings as including: income; the reward of having a job; gaining skills that are transferable to other employment situations; becoming reinvolved in the routine of work; learning about themselves and how to handle a variety of difficult situations; the challenges offered that are not available in “sheltered” work settings; personal growth; and friendship. The costs, or negative features of their work are described by Mowbray et al as including: dealing with difficulties, for example clients who were not cooperative, and the frustration and anger the peer support specialists felt often at these times; costs to their well-being, for example experiencing job stress, uncertainty about how to do the job, lack of support

from supervisors and administrators, and a feeling of worry relating to the responsibility the position entailed; and finally the challenges of determining and maintaining boundaries.

There is clearly a gap in the literature about mental health consumer involvement in evaluative research. While much has been written about the importance of having consumers involved, description and explanation of what this process means to consumers is limited. While greater acceptance of the need for genuine consumer involvement and collaboration in research is becoming more broadly accepted, it is important to understand more about what it is like for consumers. Currently no model is available that describes what is experienced by consumers becoming researchers, providing consumers and other researchers with a framework for making consumer research successful. The literature I have reviewed here indicates, however, that filling research roles, like other work roles, may play a part in assisting consumers define a hopeful, active self who can anticipate a positive future.

## Conclusions

I began this chapter by describing the broader research context within which this qualitative study is being conducted. Specifically, I described the Consumer Evaluation of Mental Health Services Project (CEO-MHS) and the roles Consumer Researchers played in this project. I then discussed the broader research context within which the CEO-MHS project sits, reviewing evaluation literature with a specific focus on mental health service evaluation. I concluded from this review that a modern approach to evaluation is not met by the current approaches reported as in use in mental health services, although I noted some exemplary exceptions. In connection to this issue, I then explored the literature pertaining to consumer involvement in evaluation, and the role of mental health consumers as researchers. I found few studies describing the experiences of consumers as

researchers, despite a strong thesis within the evaluation and mental health literature that consumers should be involved as researchers in evaluative research.

In the next chapter I will consider approaches to understanding mental health and mental illness, focusing on the implications the differing approaches have for involving consumers as researchers.

## CHAPTER 3

### MODELS OF MENTAL HEALTH AND ILLNESS: THEORETICAL UNDERPINNINGS OF THE MODEL DEVELOPMENT

In this chapter, I will examine a range of theoretical frameworks guiding mental health services and mental health research, with specific attention to the implications these carry for working with consumers. In conducting this research, I needed a theoretical stance which allowed me to rely on consumers' own meanings developed from their experiences of using mental health services and of becoming researchers, and which provided me with a way to understand their psychological changes. I will begin by discussing the medical model and some of its limitations. This is the dominant mode of thought on which mental health services, and service research, are based. I will argue that an alternative way of viewing mental health consumers is necessary as the supporting framework to: a. conduct research with mental health consumers; and b. develop a model of consumers becoming evaluation researchers. I will then discuss a number of alternative theories or models that have been applied to mental health service provision and research. I will also outline the assumptions from which my model is being developed, by introducing personal construct theory (Kelly, 1991/1955). This theory provides a way of viewing mental health, and experiences of psychological distress, in contrast to a more traditional, medical model approach to people diagnosed with mental illness (Malins, Oades & Viney, 2003). I will conclude the chapter by examining specific aspects of the theory of personal constructs, which are particularly useful to understanding the processes and experiences for consumers becoming evaluation researchers.

### Theoretical Frameworks in Mental Health and Mental Health Services

In order to develop a model of mental health consumers becoming evaluation researchers, I need to explore the supporting assumptions on which mental health services are based.

Mental health services, and thus every function and aspect of any service, are always influenced by some theoretical position about people, and the nature of mental



health and illness. There are several approaches, from a range of conceptual and practice areas that could be, and are, applied to mental health services and care. Theories of nursing, social work, counseling, clinical psychology and service models can all be applied to mental health services (Farhall et al, 2001; Horsfall, Stuhlmiller & Champ, 2002; Shanley, Jubb & Latter, 2003). However, there is a consensus within the literature that services have a long history tied to the traditional medical model (Ahern & Fisher, 2001; Kerr, Birkett & Chanen, 2003; Shanley et al, 2003). In Australia, and overseas, while much of our mental health policy has moved beyond a traditional medical model approach, now with recognition of consumers rights and determination of their own care at its forefront (Australian Health Ministers, 1998 & 1997; Department of Health (London) 2001 & 2003; US Department of Health & Human Services, 2001), practice remains largely influenced by the medical model (Shanley et al, 2003).

#### The Medical Model: its Limitations and Implications for Consumers in Mental Health

Traditionally, people diagnosed with a mental illness have been construed through a medical framework. This tradition is one of viewing consumers' experiences in terms of pathology, and diagnosis occurs using traditional nosological categories from which treatment is determined. The aim of treatment within this framework is symptom reduction, ideally cure. It is important to consider the implications this has for how consumers are viewed, and the possibilities this allows for their involvement in services and research.

As the dominant mode of construing within mental health services, the medical model has established the tradition of discounting consumers' views (Horsfall et al, 2002; Shanley et al, 2003). This has had a clear impact on how services have been evaluated, whose views have structured the evaluative tools used, and what roles consumers have been offered in research, services, and their own treatment. This view has effectively

placed consumers in a passive role of being unable to effect change, influence service planning, or even the course of their own treatment (Lloyd & King, 2003).

Consumers within this tradition are “patients” viewed as incapable of defining their own needs, requiring others to make life decisions for them, despite evidence to the contrary (Buhler, Oades, Leicester, Bensley & Fox, 2001; Chamberlin & Rogers, 1990). Behaviour, experiences, and expressions of distress are categorically classified, and with this labelling flow two implications: a transfer of ownership of the person’s body to the “medical system”; and the deeply negative, socially, and medically constructed connotations of a “diseased mind” (Susko, 1994). Parsons (1959, cited in Bates, 1979) describes four major implications the disease model of “mental disorder” has for the person labelled. These include: 1) being exempted from many typical daily expectations; 2) needing to take no responsibility for their situation; 3) they must want to try and get well; and 4) they must hand over responsibility and power to whoever society believes appropriate/competent to help them get well (that is, the mental health services). Within a tradition like this, possibilities for consumers to take on active responsibilities – for genuine involvement in any aspect of mental health research and service provision – can only be severely limited and tokenistic.

While the disparities between professional and consumer views are being increasingly considered, and inclusion of consumers in evaluating services is encouraged at a policy level, frequently these processes are still couched in the parlance and ideology of the medical model. For instance, medication compliance (or treatment compliance) – a concept used in arguments supporting involvement of consumers in the process of developing and conducting evaluations of services (Lowry, 1998; Playle & Keeley, 1998) - is grounded in the notion of paternalism and expertise of professionals inherent in the medical model. One of the major problems consumers indicate is the power-differential that is the foundation of the traditional construction of mental illness (Bassman, 2000; Lynch, 2000; Unzicker, 1989). Inclusion of consumers in any aspect of the service,

(evaluation research, and evaluation of mental health services included) for reasons relating to issues like compliance, in no way challenges the established interpretations of people's experiences, or the power imbalances experienced in dealing with mental health services. Involving consumers in any aspect of service planning, delivery, evaluation, or research, but not challenging the traditional views of "mental illness" seems to be moving only a small way towards rectifying the broader problem.

The Diagnostic and Statistical Manual of Mental Disorders (DSM) is currently the dominant diagnostic tool used by clinicians, researchers, and services. A number of difficulties with the categorical model of classification represented by the DSM-IV (American Psychiatric Association, 1994) have been identified (Livesley, Schroeder, Jackson & Jang, 1994; Raskin & Lewandowski, 2000; Widiger, 1997). Categorical models of classification have been heavily criticised for arbitrary distinctions between "normality" and "disorder." Authors such as Widiger (1997) and Livesley et al (1994), argue for a more dimensional classification system. Raskin and Lewandowski (2000) also argue that, from a personal construct perspective, that a major problem with the DSM is its failure to be represented as *a construction* of disorder, instead, becoming a dominant viewpoint that preempts other interpretations.

Critiques of the medical dominance of the mental health field have been extensive (Barney, 1994; Shanley et al, 2003), with some notable challenges being the biopsychosocial model (Engel, 1977) and more currently, the recovery movement (Ahern & Fisher, 2001; Jacobson & Curtis, 2000). The theory of personal constructs offers similar criticism (Kelly, 1991/1955; Raskin & Epting, 1993). One of the major criticisms levelled at the medical model relates to its objectivist approach (Cohen, 1993; Farber, 1990; Kelly, 1991/1955). The medical model ignores the context within which both consumers and clinicians exist. However, social and cultural contexts influence both groups (Raskin & Lewandowski, 2000). The way consumers are understood and interpreted by the mental health system/professional, as well as others in their lives, is

assumed to have no influence by the premise of “objectivity” (Cohen, 1993; Farber, 1990). Inherent in the medical model is an assumption that a neutral, objective gaze is possible (Cohen, 1993). Implications of this “objectivity” flow through to the establishment of the “expert” role, the mental health professional who is able to take this objective gaze, and the passive “patient” role, the individual who needs the “expert” to take control for them (Wampold, Ahn & Coleman, 2001).

That the medical model itself, and the DSM-IV system of diagnosis, are themselves social constructions, seems to have been largely lost (Barker, Reynolds & Stevenson, 1998; Cohen, 1993; Farber, 1990; Hall, 1996; Raskin & Lewandowski, 2000; Susko, 1994). The focus on objectivity and the social and historical context of the adoption of the model have resulted in the use of this construction as a firm entity (Sarbin, 1990). Critics of the medical approach advocate a more contextual perspective, suggesting, as the consumer literature does, that more than just biological factors need to be considered (Raskin & Epting, 1993; Susko, 1994; Wampold et al, 2001). These criticisms apply not only to the influence the model has had in service structure and care approaches, but also to research conducted. As Hall (1996) notes, a flow on to research in these areas is consideration of limited factors, objectifying, and reliance on nomothetic rather than ideographic knowledge. The model is criticised as being highly limited, because personal and social meanings are not considered; information that is incompatible with the model is excluded, severely limiting the options available when working within this system (Cohen, 1993).

While criticism of the medical model has occurred over decades, as yet, no alternative has been adopted as the philosophical position from which public mental health services operate (Barney, 1994). The medical model is embedded within the economic and social structures of the Western world, and currently, these are still aligned to maintain it as the dominant model (Cohen, 1993; Horwitz, 2002). Barney (1994, p. 28) goes so far as to say “...there is little reason to expect critique to have much impact at this

time, given the undiminished power of this system and its supports...”. Despite this, he suggests that the critiques, and proffered alternatives, within themselves are also limited and so have not been adequate to challenge the medical model (Barney, 1994; Cohen, 1993; Shanley et al, 2003). Telford and Faulkner (2004) raise similar concerns about the effect of the medical model has as a barrier to genuine consumer involvement in services research.

### Exploring Alternatives to the Medical Model

A range of alternatives to the medical model exist, in the form of psychological theories that make assertions about people and their behavior, which have impacted historically on mental health service provision. These include the psychodynamic approaches (Freud, 1966; Benner, 1997), encompassing a range of theories that emphasise different aspects of mental dynamics (Bootzin, Acocella & Alloy, 1993). Psychodynamic theory, generically, differs from the medical model in that it is open to, and indeed requires, idiographic knowledge, not just nomothetic knowledge. Additionally, psychodynamic theory introduces the concept of mental health as a continuum, rather than a dichotomy: the implication being that every person fits on this continuum (Bootzin et al, 1993). For mental health service provision, research, and the roles of consumers in both, this means that consumers’ experiences come to the fore, unlike the medical model. The deterministic foundations of the psychodynamic theories fit strongly with the medical model however, and using these approaches, a power differential between provider-consumer, researcher-researched is still created. Insights and interpretations of the consumers’ experiences are provided by the therapist, not the consumer themselves, thus the “expert” analyst role is created (Davidson, 2004).

Behavioural and cognitive behavioural models (Mahoney, 1995; Meichenbaum, 1995), which have experienced great prominence in Australian health services, as well as internationally (Crossley, 2000) also provide an alternative foundation for mental health

provision and research to the medical model. Underpinning behavioural (Watson, 1925; Skinner, 1965) and cognitive (Ellis, 1977 & 1989) models have been heavily criticised, and while combining these into cognitive behaviourism overcomes some of the limitations each approach holds as a separate psychology, many of these criticisms also apply to cognitive behavioural approaches. In terms of providing a useful theory to underpin collaborative research with mental health consumers, cognitive behaviourism does not introduce the necessary alternatives to the medical model. In common with the medical model and psychodynamic psychology, cognitive behaviourist approaches also establish a clinician as “expert” model for therapy, which flows through to approaching research and service provision. Active roles for consumers are not created from this perspective. Like the medical model, cognitive behavioural theory is deterministic, and proposes a neutral “objective” stance as possible, and thus consumers’ experiences and meanings are not valued. Instead, the “objective” clinician holds the answers necessary to overcome psychiatric distress.

Another important alternative to the medical model, is the social model of disability, being advocated since at least the 1960s (Crossley, 2000). Social models challenge the individualised perspectives of the medical model, and the other alternatives to it described above, by asserting “that people are disabled by economic, social and environmental barriers and by the (often unintentional) discriminatory practices and attitudes which are still a feature of our society.” (Grove, 1999, pp. 133 – 134). According to Tew (2002), a social model proposes that mental distress may typically be understood as a response to problematic life experiences. The values underpinning social models of mental distress create different opportunities for working with consumers to those employed by the medical or cognitive behavioural approaches. Tew (2002) argues that the value base of a social model should be explicitly focused on partnership with consumers, working toward outcomes defined by consumers. Tew also argues that at the value base of a social model needs to be a commitment to hear and take seriously

consumers own meanings, an explicit challenge to traditions of mental health service provision which have sought to classify, diagnose and interpret experiences for people. Tew defines this as an “anti-oppressive practice” in that it is based in people’s own experiences, and requires a language different to that of the medical model – “one which situates the user as someone who is active and responsible, and draws on the terms that have been proposed and negotiated by service users themselves.” (Tew, 2002). Tew suggests that this requires a shift from discourses of “mental illness” to “mental distress”, from “symptoms”, and from “treatment”.

The biopsychosocial model, (Engel, 1997) essentially draws together the biological, cognitive and social models in understanding mental illness and psychiatric distress (Allen, 1998). This model is an important divergence from the medical model, as this model carries the assumption that people are part of whole systems (Pilgrim, 2002) and these whole systems interact within complex contexts. The biopsychosocial model differs from the medical model in its stance of wholism, and non-reductionism. The biopsychosocial model also moves away from the determinism featured in the medical model and other alternatives discussed above. Consumers, from this perspective, are seen as whole people, much more than symptoms, or biology.

I will now focus in greater depth on the alternatives to the medical model, offered by empowerment and recovery theory, and personal construct theory. As the following discussion establishes, I believe that to work with consumers of mental health services becoming researchers, and to hear and understand their experiences, these alternatives provide me with the most helpful theoretical possibilities. As I will indicate, empowerment and recovery theories are consistent with a personal construct approach.

*Empowerment models.*

Empowerment and recovery theories are closely tied, both being strongly influenced by the mental health consumer movement (Clark & Krupa, 2002; Linhorst & Eckert, 2003). In fact, each is respectively sighted by authors as a major influence on the other (Ahern & Fisher, 2001; Linhorst & Eckert, 2003). Empowerment is a complex concept, with multiple definitions (Clark & Krupa, 2002; McLean, 1995), and as McLean (1995) notes, with different operational meanings for different groups within mental health.

Clark and Krupa (2002) suggest that the common elements of definitions of empowerment include: participatory processes that increase personal control and critical thinking, action and power sharing, dignity and equity through social change, and the mobilisation of resources. These authors also discuss the basis current understandings of empowerment have in power theory. They argue that theories of power suggest that poor mental health may be a product of social structures, and power theory focuses on the forms power can take, and its absence. Empowerment approaches and social approaches to mental health and psychiatric distress can be seen as related at this level.

Braye and Preston-Shoot (1993) discuss two different approaches to empowerment: anti-discriminatory frameworks and anti-oppressive frameworks. They argue that anti-discriminatory practice links with a two-dimensional use of power, and seeks change within the rules, procedures and structures already established. Essentially, they argue that this approach to empowerment respects the medical model of distress, however works to ensure that power and resources are not used differentially between groups. Braye and Preston-Shoot (1993) argue that alternatively, anti-oppressive frameworks involve active pressure for changes to the rules, procedures and structures in place, with an emphasis on changing oppressive legal structures and practices. They



suggest that this model works with three-dimensional power, explicitly exploring political power in the mental health field. These authors argue that anti-oppressive empowerment frameworks challenge biopsychosocial models of mental health, and recognise alternatives to the medicalisation of psychiatric distress.

Nelson, Lord and Ochocka (2001) discuss the “empowerment paradigm” in relation to mental health. They note that this “paradigm ...sees mental health as a construct that needs to be addressed beyond the mental health system.” (p. 126). Nelson et al (2001) go on to discuss the need for political and community changes to enhance empowerment and mental health, and from this perspective, an empowerment paradigm is consistent with frameworks such as action research, or participatory action research. Nelson et al note three common elements to various definitions of empowerment, including: the personal dimension of both perceived and actual power; the social embeddedness of empowerment, in which empowerment can be conceived of as a process of involving ‘self in community’; and that empowerment involves access to valued resources. They also discuss the similarity between definitions of “empowerment” and “mental health”. However, they note that there is a distinction, defining empowerment as “opportunities for and conditions that promote choice and control, community integration and valued resources” while defining mental health as “the development and acquisition of choice and control, community integration and valued resources.” (Nelson et al, 2001, p. 127). These authors argue that, while empowering situations “set the stage” for mental health, there is not a linear relationship between the two.

Nelson et al (2001) developed a grounded, ecological, model of the relationship between empowerment and mental health, in which they suggest that the relationship between the two concepts is mediated by different ecological systems. They propose that choice and control is mediated from empowerment to mental health by the individual and their relationships; community integration by organisations and the community; and

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valued resources mediated from empowerment to mental health by social policy (Nelson et al, 2001).

While definitions of empowerment vary, and the different perspectives amplify differing meanings, broadly, the literature appears to converge meta-theoretically, on a monist view of people with a constructivist epistemology, and thus an wholistic focus. An empowerment perspective is clearly idiographic, at the same time holding strong social and cultural contextualisation.

Rapp et al (1993) discuss the influence an empowerment perspective has on research in mental health, noting that work from this perspective: focuses on understanding individual characteristics as well as the interaction of individuals and environments; and involves genuine collaboration. Consumers should be involved from the inception of the research, helping develop and formulate the research. The data collected should be from consumers, however, this needs to extend to consumers also collecting the data whenever possible. Rapp et al also discuss a willingness to hear consumers' views, on the part of non-consumer researchers, as a necessary component of genuine collaboration; different perspectives are acknowledged, but research from this perspective maintains the position that it is consumers' views that need amplification; outcomes, approaches, language, and measures should be consistent with the empowerment framework, be reflective of consumers, and relevant to their perspectives.

While an empowerment agenda underlies much contemporary policy and planning rhetoric of mental health services (Rapp et al, 1993), there is general agreement that this agenda is often not reflected in practice, or research, within the mental health field (Linhorst & Eckert, 2003; Rapp et al, 1993). Indeed, Rapp et al (1993) observe that often research actually undermines it. Clark and Krupa (2002) discuss some of the difficulties for the empowerment agenda, with the overarching medical model backdrop to mental health practice. While an empowerment perspective presents strong alternatives to working with mental health consumers, and opens possibilities specifically for working

with consumers in research, a more comprehensive psychological theory is necessary to construct an understanding of consumers' experiences becoming researchers.

*Recovery models.*

A contemporary approach to providing mental health services is based on a recovery vision. The very concept of recovery is in contrast to assumptions of the medical model. The basic assumptions of a recovery-focused mental health system involve: a belief that consumers hold the key to recovery, not professionals; that professionals may provide support to consumers, however, recovery is just as possible without professional intervention; that good, human, relationships are one important facet of the recovery process; recovery is not a linear process; recovery is also about consequences of the illness, not only symptoms; that the concept of recovery is not synonymous with a finite, asymptomatic state, which means recovery can occur even though symptoms recur (Anthony, 1993; Anthony, 2000). As Barton (1998, p. 172) argues:

Recovery involves the idea that consumers assume responsibility for their lives by making choices and learning from that process; the corollary is that professionals must affirm and nurture the process of consumer choice.

Models of recovery carry a strong empowerment approach, as the model described by Ahern and Fisher (2001), called the Empowerment Model of Recovery, demonstrates. They cite that research points to principles of recovery including: the formation of supportive relationships with people; peer support; empowerment; and wholistic health. Unlike a medical model approach, the empowerment model of recovery stresses the importance of understanding people's meanings about what is happening to them, or the way they are behaving, assuming that there is always personal meaning, even in what may seem to be unusual behaviour to others (Ahern & Fisher, 2001). This model places experiences labeled "mental illness" by the medical model within a developmental, social, and cultural context. Underlying this is the belief that recovery is possible.

Theoretical assumptions of this model include a constructivist epistemology, and an wholistic view of humanity, which lead to the necessity for idiographic approaches to be adopted, and at the same time a firm placement of recovery within social contexts, and personal relationships (Ahern & Fisher, 2001). A recovery orientation to service provision creates opportunities for consumers' roles within services to expand, and this orientation requires full, meaningful consumer participation in planning, developing and evaluating services.

One dispute within the recovery literature lies between proponents of a recovery view that proposes recovery is an ongoing, perhaps never-ending quest: "people are always recovering from their mental illnesses, despite becoming fully functioning members of society" (Ahern & Fisher, 2001, p. 27) and the empowerment model which asserts that recovery can be a finite state. Andresen, Oades and Caputi (2003) have offered an alternative model of recovery based on a definition of psychological recovery, which they argue is similar to the empowerment model above, but does not assert any causal theory of mental illness, and makes no claims about whether illness is present in recovery. The model proposed by Andresen et al (2003), however, pays little attention to the social and cultural context of recovery, which are focal in other models and discussions of recovery (Ahern & Fisher, 2001; Anthony, 1993; Deegan, 1996; Ellis, 2003).

Within many discussions of the concept of recovery are perspectives consistent with constructivist theories generally, and specifically personal construct theory. Townsend and Glasser (2003), for example, note the centrality the belief in options from which to choose has in recovery. This perspective is consistent with, and parallels closely the concept of constructive alternativism (Kelly, 1991/1955), one of the axial theoretical concepts within personal construct theory, which will be discussed in detail later in this chapter.

Both empowerment and recovery models fit within broader health or well-being conceptualisations (Hartwig & Myers, 2003), as opposed to the deficit approach which underlies the medical model (Clark & Krupa, 2002; McLean, 1995). These perspectives emphasise consumers' strengths and assets, and place consumers' views centrally in their own lives, and in effective mental health services and research (Hall, 1996; Rapp et al, 1993).

### *Personal Construct Theory*

Personal construct theory offers a helpful alternative approach to mental illness and psychological distress (Button, 1985), and so holds implications for mental health services and evaluation research. Personal construct theory understands consumers as meaning-making people – this approach focuses on their meanings, rather than their behaviour as a symptom of something beyond their control (Bannister, 1983<sup>a</sup>; Button, 1985; Kelly, 1991/1955).

Personal construct theory offers an extensively elaborated alternative theory, which is not uniquely aimed at making sense of behaviour and experience that may be labelled “mental illness” within the medical model, but like the psychodynamic approach, applies to everyone and so is reflexive (Kelly, 1991/1955; Winter, 1992). Personal construct theory is highly consistent with the empowerment and recovery approaches I discussed above.

Personal construct theory challenges the very foundations of the medical model, being based on assumptions counter to those of the traditional framework (Raskin & Epting, 1993; Winter, 1992). The philosophical underpinning of constructive alternativism holds that many interpretations are possible, and that any interpretation, at some point, could be revised or replaced with a more satisfactory alternative interpretation (Kelly, 1991/1955; Winter, 1992). Personal construct theory consists of a Fundamental Postulate and eleven corollaries (Kelly 1991/1955). The Fundamental

Postulate states that people are primarily concerned with the anticipation of their worlds, as they actively engage in defining their personal realities. The eleven corollaries describe the structure and organisation of meanings, the processes of meaning-making, and the social context within which meanings are created.

As well as offering a systematised framework for understanding consumers, this theory acknowledges the subjectivity of any assessment, or indeed any construction of the world; everyone is involved in *interpreting* the world (Raskin & Epting, 1993). The implications of this framework for consumers are profound. Being grounded in the subjective rather than objective, with a reflexive stance, there is no scope for the development of “expert” and “patient” roles. Rather, as Bannister (1983<sup>b</sup>) reports, Kelly explicitly offers the metaphor of academic supervisor-researcher for the clinician-consumer relationship. The expertise, then, does not rest with the clinician alone, as it does with the medical model. Instead, when this metaphor is used, there is “differential and complementary expertise”, in which the consumer is expert in his or her own experiences. The clinician’s expertise relates to experience in exploring issues (Bannister, 1983<sup>b</sup>, p145). This metaphor makes way for consumers to play an active role in their own lives, and indeed in mental health services. The role of a clinician is not to classify or categorise an individual or their behaviour, but to attempt to understand the consumers’ ways of construing their worlds, and join them in a journey of reconstruing (Kelly, 1991/1955; Winter, 1992). This approach is similar to Guidano’s Personal Meaning Organisation (1991).

Transitive diagnosis, in contrast to traditional, medical model diagnosis, recognises the flux of people’s attempts to make sense in and of their world (Kelly, 1991/1955; Raskin & Epting, 1993; Winter, 1992). The term “transitive diagnosis” implies that personal construct theory focuses on “the bridges between the person’s present and future” (Kelly, 1991: Vo. 2. p. 153). One important difference between transitive diagnosis and the framework of diagnosis offered by the medical model is that

the former is fundamentally process-oriented, as opposed to static. Transitive diagnosis resonates with a dimensional style of diagnosis, an issue remaining under debate (Livesley et al, 1994; Widiger, 1997). Another difference, central to the concept of transitive diagnosis, is the unique way people construe their world (Raskin & Epting, 1993). As people interpret and experiment, the construction processes used represent that person's best available means of anticipating (Winter, 1992). When people experiencing psychological distress are considered, this approach implies that while the usefulness of the interpretations they are utilising may be questioned, a person experiencing psychological distress is involved in the same interpretative, anticipatory process as people currently functioning optimally (Winter, 1992).

Bannister has played a focal role in applying personal construct theory to mental health and making sense of psychological distress (Bannister, 1985). His work in testing the serial invalidation hypothesis of thought disorder, and experimenting with serial validation as a way of reversing thought disorder, clearly place consumers' construct systems and reactions to them central to these experiences of psychological distress (Bannister, 1971; Bannister, Adams-Webber, Penn, & Radley, 1975).

Other alternatives to the medical model that have been offered are criticised by Barney (1994) as being grounded in the same individualistic approach to psychology that maintains the medical model. Barney suggests that this is the fundamental limitation of the alternatives, and why they have not sufficiently challenged the traditional framework. Within personal construct theory, individuality and commonality are central to understanding a person (Kelly, 1991/1955; Walker, 1996). Individual's systems of meaning develop "by and in our interactions with others and develops to a large extent to make sense of ourselves and those others." (Walker, 1996, p. 13). Meanings about self and the most influential values and beliefs are crucial in defining people's relationships with others (Landfield & Leitner, 1980). Within personal construct theory there is no individual as distinct from the social; all of our systems of meaning are tied to

interactions with others (Kelly, 1991/1955; Bannister et al, 1975; Bannister, 1983<sup>a & b</sup>; Walker, 1996). As Warren (2000) has argued, the focus of personal construct theory in clinical psychology tends to stress the individual's meanings, which can create ambiguity. However, Warren argues: "the wider theory...has both a specific role for shared meanings and accommodates the fact of a social context that has its own collective pressures to reach particular understandings." (Warren, 2000, p. 86).

### Some Ways Forward for Evaluation Research with Construing Consumers

Personal construct theory helps to make sense of the discrepancy between consumer and professional views, that authors like Perkins (2001) highlight, and provides an alternative way of approaching consumers' psychological distress, and any associated disability and disadvantage. The distance between consumers' and professionals' constructions can be narrowed as professionals are invited to attempt to understand consumers' meaning systems, rather than adopt DSM-IV diagnostic categories and thus construe people preemptively (Raskin & Lewandowski, 2000). Personal construct theory invites collaborative action and understanding in a clinician-consumer relationship, it invites collaboration at a service level, between consumers and the service providers, and invites collaboration at a research level, between consumers and researchers (Viney, 1987). The mutual orientation model of data collection identified by Viney (1987), which I discuss in detail in Chapter 6, highlights this theme of collaboration in research further.

Reflecting the clinician-consumer relationship, the service-consumer relationship embodies "differential and complementary expertise". At this broader level, consumers remain experts in their own experiences, and this expertise is core to service development and improvement. The expertise mental health services contribute relates to providing resources, managing systems, enabling an environment where consumers, and clinician-consumer relationships, are able to achieve their goals. None of the disempowering connotations of inability, irrationality and passivity that dominate a medical construction



of consumers' experiences are inherent from a personal construct theory perspective. Importantly, none of the assumptions of hopelessness, of static being, are invited by this way of construing either, creating the opportunity for consumers to become active participants in shaping their services. If the view that consumers are experts in their own experiences is adopted, consumers are placed at the centre of any attempt to evaluate services, therefore no longer asked to passively consume services. Partnership between services and consumers is required to adequately evaluate a service, if we take as a basis the interpersonal and social construction of meaning and understanding. At a fundamental level, this challenges the passive role typically offered to consumers by mental health services.

The implications of this meta-theory for conducting research are that it places consumers centrally in research processes, and provides a set of guiding principles for conducting this style of collaborative research. Collaborative research, with consumers taking on active research roles becomes possible. The literature reviewed in Chapter 2, demonstrated that our understanding of what it is like for consumers' to be involved in research, as researchers, is highly limited at this time. More specific aspects of personal construct theory, which can be used to help conceptualise the processes involved in becoming a researcher, will now be discussed in detail.

#### A Description of Personal Construct Theory Concepts that Apply to Developing a Model of Mental Health Consumers becoming Evaluation Researchers

While my aim is not to devise an a-priori theoretical model, but to develop a model of consumers becoming evaluation researchers based on information collected from the consumers in the CEO-MHS team, I will, however, use personal construct theory to assist me in my attempts to understand, make sense of, and organise my perceptions of this information. Therefore, my objective is not to develop a theoretical

model to be tested, but to outline aspects of the theory I anticipate will be of use to me in developing the model from the data.

Personal construct theory provides me with the basis from which I work: people are active interpreters of their worlds. It is essential, then, to try and access people's own interpretations, in my case, to ask consumers about their experiences as consumers of mental health services, and as researchers. Qualitative approaches are highly consistent with personal construct theory, however are certainly not unique to this theoretical approach. I will discuss qualitative research approaches and their fit with personal construct theory in more detail in Chapter 5 of this report. Personal construct theory helps me make sense of how my views and those of my participants and co-researchers will be at times similar, and at other times different, and informed our choice as a team to focus on consumers' views rather than those of academic researchers, or mental health professionals. This concept, along with one of reflexivity, which is central to personal construct theory as well as other philosophies that support qualitative methodologies, carries the implication that I need to acknowledge that, while ever I am trying to access other's interpretations, I am using my own to do so.

### *Personal Construct Concepts of Transition and Change*

Kelly's (1991/1955) theory of personal constructs is centrally about people's attempts to predict and anticipate, and so choose their life path, captured in the metaphor of the person as scientist (Kelly, 1991/1955). I introduced this metaphor earlier when discussing the work Bannister undertook and the alternate metaphors available for clinicians and clients. Following this analogy, peoples' anticipatory constructions are hypotheses, their behaviour the experiments they use to test their predictions (Dalton & Dunnett, 1992; Tschudi, 1983). Central to this approach is the view of people, and their construct systems, as dynamic and evolving. Kelly argues that: "the successive revelation of events invites people to place new constructions upon them whenever something

unexpected happens. Otherwise one's anticipations would become less and less realistic" (1991, pp. 50-51). Changes in people's lives, in their environments – indeed life transitions – require construct change:

Constructs enable a person to hear recurrent themes in the onrushing sound and fury of life. They remain relatively serene and secure while the events above which they rise rumble and churn in continuous turmoil. Yet constructs themselves undergo change. And it is the transitions from theme to theme that most of life's puzzling problems arise. (Kelly, 1991, p. 359).

The way people's construct systems are organised and operate, and their emotional experiences, are closely linked to experiences of change and transition, according to Kelly (1991/1955).

Parameters for change are outlined by Kelly in discussions of how peoples' meaning systems are organised and related. Meanings about the world are organised into hierarchical systems – with some meanings more superordinate to others, subsuming other sets of subordinate meanings. Thus, superordinate constructs hold broader implications for people's overall outlook and are more abstract, whereas other constructs within their system may be more peripheral, subordinate and generally more concrete. The extent to which change in people's meanings can occur is impacted by how permeable those meanings that are superordinate are (Kelly, 1991/1955). Kelly states "the variation in a person's construction system is limited by the permeability of the constructs within whose range of convenience the variants lie" (1991, p. 54). This statement implies that the extent to which people's anticipations of the world (their constructs) allow them to make sense of new experiences - events, people, things - affects how they experience and change: for change to occur, people need superordinate constructs which are permeable. People's construct systems evolve and change, to encompass new experiences, but only within the constraints imposed by their current meaning system.

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*Emotions that Accompany Transition*

Emotion holds a unique place in the theory of personal constructs (Kelly, 1991/1955), being equated with change in the construct system: emotion is a person's experience of change, or its possibility (Bannister & Fransella, 1980). In discussing experiences of transition, Kelly emphasised four emotions as particularly relevant. While these emotions are labeled with traditional terms, Kelly focuses on the meaning of the situation for the person experiencing change, rather than the meaning for external observers. Kelly discusses the emotions of threat, fear, anxiety and guilt, and I will look at each respectively now.

Threat, Kelly defined as: "the awareness of imminent comprehensive change in one's core structures" (1991, p. 361). Threat will occur when consumers' recognise that their most influential meanings are seriously inconsistent with the events they are involved in, and they find themselves on the threshold of deep changes that have far reaching implications. People may experience threat in a range of situations, however, the prospective change they anticipate must be substantial. Threat could be experienced when a person is diagnosed with a serious mental illness, but could also be experienced when a person faces the challenges of working as a researcher.

Fear is defined in personal construct theory as: "like threat, except that, in this case, it is a new incidental construct, rather than a comprehensive construct, that seems about to take over." (1991, p. 364). The change anticipated when experiencing fear is still about self construing, however, fear is associated with anticipating change where fewer aspects of the self may change. In contrast, threat is linked to anticipating broad change, where almost everything about a person might change (Kelly, 1991/1955). If a person experiences fear, not threat, they can still hold a sense of general control of more superordinate aspects of their construing, however with threat, their basic identity is at stake (Kelly, 1991/1955).

Within the psychology of personal constructs, the term anxiety has a very specific meaning, and refers to “the recognition that the events with which one is confronted lie outside the range of convenience of one’s construct system” (1991, p. 365). That is, people experience anxiety when they become aware that they cannot make sense of the situation they experience, or anticipate what may happen: where their constructs do not apply (Kelly, 1991/1955). People are able, however, to tolerate some level of incompatibility within their construct system: how much incompatibility each person can tolerate depends on the permeability of their superordinate constructs (Kelly, 1991/1955). Anxiety, in this theory, is a precondition to making revision of one’s construct system. A linear relationship between the amount of anxiety experienced and revision is not posited, however, as Kelly (1991/1955) suggests, too much anxiety could lead to *no* change.

Kelly (1991/1955) described guilt as a persons’ perception that they are not maintaining a role they believe other people expect from them. In personal construct theory, people are understood to construct central meanings about themselves, based on the roles in which they believe others’ expect of them, and some of these roles are central to maintaining an integrated sense of self (Kelly, 1991/1955). Guilt relates to a person’s social understandings, and is a clear example of how the theory of personal constructs views people in their social contexts.

In his discussion of transition, Kelly also outlined the concept of aggressiveness as an aspect of construct systems in a state of change. He defined aggressiveness as actively seeking to expand the range of experiences in which to engage. Aggressiveness can be seen as a mechanism used to test and elaborate people’s sets of meanings about themselves and their worlds.

McCoy (1977) extended Kelly’s concepts of the dimensions of transition to include elaboration of positive affect. Positive affect is associated with people’s recognition that their meaning system does indeed help them successfully make sense of the events they experience. Thus, McCoy defined positive emotions as relating to

awareness of confirmation of constructs. She defined the emotions of love, satisfaction, happiness, complacency, contentment and self-confidence. Love and happiness both relate to confirmation of people's most central meanings, with happiness defined as validation of a portion their most central set of meanings about themselves (core structure). Satisfaction, McCoy defined in terms of validation of non-core structure. Self-confidence has been defined as people's awareness that their view of themselves fits well with the role they consider others expect them to fill. Contentment is the opposite of anxiety, being defined as awareness that the events with which people are confronted can be understood using the meanings they already hold (that is, they are within the range of convenience of their construct system). In addition to McCoy's work on positive affect, Epting and Amerikaner (1980) introduce the concept of hope, characterised by a readiness to engage in an encounter – "to affect and to be affected" (p. 60). Hope implies a willingness to interact with the environment and orientation towards movement into the future. These authors argue that hope is thus a feature of optimal functioning (Epting & Amerikaner, 1980).

### *Confirmation and Disconfirmation*

As people make hypotheses, attempting to predict and make sense of the world, the theory of personal constructs, with its person as scientist metaphor, suggests that their predictions may be either confirmed (validation) or disconfirmed (invalidation):

A person commits himself (*sic*) to anticipating a particular event. If it takes place, his anticipation is validated. If it fails to take place, his anticipation is invalidated. Validation represents the compatibility (subjectively construed) between one's prediction and the outcome he observes. Invalidation represents incompatibility (subjectively construed) between one's prediction and the outcome he observes. (Kelly, 1991, p. 110).

As Button (1996) explains, this confirmation and disconfirmation is best understood as people's theories about their worlds being strengthened and weakened respectively. Button emphasises, also, the subjective nature of confirmation and disconfirmation.

Walker, Oades, Caputi, Stevens and Crittenden (2000) have extended an understanding of validation and invalidation, to include the concept of non-validation. Non-validation, they argue, is a further alternative which is the choice not to engage in testing constructions. Experiencing validation, and invalidation, plays a central role in construct change.

### *The Creativity Cycle*

The Creativity Cycle is one of the ways personal construct theory suggests people create constructs to help make sense of experience, and anticipate future events. As the name implies, the Creativity Cycle relates to how a person develops new ideas (Kelly, 1991/1955). It is an aid to people's experimentation. Kelly describes the Creativity Cycle as beginning with "loosened construction and terminates with tightened and validated construction." (1991, p. 388). During loosened construction, a person considers alternative pathways and approaches, shifting their approach to the problem or situation under focus. Alternative constructs generated can then be tested and through testing, they thus become "tightened".

### *The Experience Cycle*

In addition to the way peoples' construct systems are organised and the emotions that accompany transition, Kelly also described the Experience Cycle as an important process in experiences of change. The emotions described above which are indicative of change, are likely to be experienced as part of engaging in the Experience Cycle.

The Experience Cycle can be viewed as an overall framework of the process of people's experiments. Experience is conceptualised as a cycle involving five stages. In the first stage, Anticipation, people formulate a prediction concerning a particular event.

The second stage of the cycle is Commitment, and at this stage people fully involve themselves in this anticipation. The Encounter stage involves full engagement in the experience: it entails open and active experiencing. In the fourth stage, people make assessments of their encounters, in relation to their original anticipation: that is, they are aware of confirmation or disconfirmation of their predictions. In the final stage of the cycle, Constructive Revision, people face the implications of the event, engaging in necessary revision following evaluation of the outcomes of the encounter stage. The Constructive Revision stage prepares people for fresh anticipations and further Experience Cycles (Winter, 1992).

The completion of full cycles of experience is essential for optimal functioning (Winter, 1992). Kelly states, optimal functioning allows a person to engage “fresh hopes never before envisioned” (1977, p. 9). Kelly’s concept of disorder is essentially a contrast to optimal functioning, and he defines disorder as “any personal construction which is used repeatedly in spite of consistent invalidation” (1991, p. 831). Winter (1992) notes however, in further elaborating this concept, that: “rather than disorders and optimal functioning being viewed as a dichotomy, they may, therefore, be considered to represent the extremes of a continuum concerning the extent to which a construction accomplishes or fails to accomplish its purpose.” (p. 15).

### *Interpersonal Interactions and Shared Constructs*

The final aspect of personal construct theory necessary to describe here, which is central to a theoretical understanding of change and transition, is interpersonal. Social interaction provides the testing ground – or laboratory – for people’s construct systems, allowing deeper understanding of themselves and others (Botella, 1997; Leitner, Dunnett, Anderson & Meshot, 1993; Walker, 1993). Bannister (1983<sup>a & b</sup>) argues that it is impossible to define the self adequately without taking the interplay with others into account. It is through social interaction that people elaborate and create meaning, both



about themselves and the world more broadly (Kelly, 1991/1955). The Sociality Corollary states: “to the extent that one person construes the construction processes of another, he (*sic*) may play a role in a social process involving another person” (Kelly, 1955. p. 104). The concept of sociality then, is essentially about trying to understand another’s perspective: or see the world through someone else’s eyes.

Supportive relationships from a personal construct perspective involve both commonality and sociality, and are aimed primarily at helping the other elaborate their construing and move towards optimal functioning. Koch (1985) suggests that the elaborative potential of a relationship is governed by the level of commonality, which provides evidence of important shared meanings, and sociality, or the level of understanding which provides for elaboration of those meanings. Commonality relates to the potential for sharing of common understandings. These understandings provide experience of consensual validation of the individual view/experience. They also provide a psychologically secure context in which to elaborate new meanings (Koch, 1985). Sociality implies that relationships are limited by the degree of understanding that is attempted. Koch (1985) has suggested that the ability to experience recurring cycles of commonality and sociality are key features of psychological well-being

### Conclusions

In this chapter I have reviewed theoretical frameworks that underpin mental health service provision and research. This review began by discussing the medical model as the traditional framework used in services, and research, and I discussed some of the limitations of continuing use of this as the dominant framework within the mental health field. I then discussed several alternative theories that can be applied to mental health services and research. Personal construct theory was identified as a robust alternative to the medical model, consistent with the major tenets of empowerment and recovery approaches. The theory of personal constructs provides the underlying theoretical stance I

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have adopted in conducting this research, therefore, I concluded the chapter by discussing specific aspects of the theory which I anticipate will be helpful in understanding the data collected to develop the model of consumers becoming researchers.

While my overall objective in this research is to develop a data-driven model of consumers becoming researchers, personal construct theory has influenced my broader conceptualisation of the possibilities for consumers. As the overarching framework from which I work, it has led to decisions to conduct qualitative, collaborative research, and influenced the manner in which I have conducted the research, which I examine in more detail in Chapter 5. It has led me to conceptualise the experiences of the consumer researchers in the team as possibly transitional, and so led to my research questions being focused on these processes. I construe being part of the CEO-MHS team as an experiment for the consumers involved (as well as myself), and so anticipate that changes to their constructions of the world and themselves may occur, due to their involvement. Further exploration of the concept of transition, and how it applies to this context, of consumers becoming researchers, will occur in Chapter 4. Part of this exploration will include further elaboration of a personal construct view of transition, through reviewing Viney's (1980) model of transition.

CHAPTER 4  
CHANGE AND TRANSITION

In this chapter, I will begin by highlighting the context of human change for developing the model of mental health consumers becoming researchers. I will then look specifically at the literature about experiencing transition. I will begin by considering meanings of transition and then outline some models of transition. In the previous chapter I described personal construct theory, and its implications for understanding transitional experiences. I will highlight resonances between the various literature discussing transition, and a personal construct theory conceptualisation of experiencing change. I will elaborate the understanding developed in the previous chapter, by describing more fully Viney's model of transition, developed using personal construct theory. Following that, I will then focus on experiences of work transition, reviewing literature specifically related to changes in work situations and roles.

### The Context of Human Change

Human beings are made neither of glass that breaks in the slightest ill wind nor of steel that stands defiantly in the face of devastating hurricanes.

Rather...humans...bend with environmental pressures, resume their shape when the pressures are relieved, and are unlikely to be permanently misshapen by transient experiences. When bad environments are improved, people's adaptations improve. Human beings are resilient and responsive to the advantages their environments provide. Even adults are capable of improved adaptations through learning, although any individual's improvement depends on that person's responsiveness to learning opportunities. (Scarr 1982, p. 853. cited in Mahoney, 1991, p. 13).

In developing a model of mental health consumers becoming researchers, it is necessary to examine ideas about human change. Mahoney (1991) in his review of the expansive area of human change literature notes the development and flux of knowledge, and views, about human change itself. While previously, conceptions of change focused

on early life, reflecting a funnel hypothesis of psychological development and change, Mahoney suggests that contemporary understandings have moved to a more open-ended notion of when change happens, recognising the potential for human change across the lifespan. Mahoney argues that this more contemporary view of change recognises centrally the highly individualised nature of change, and has become increasingly concerned with dynamic change processes, rather than fixed sequence, predetermined stages of development.

### Experiencing Transition

Hopson and Adams (1976) define transition as: “a perceived discontinuity in a person’s life space” (p. 7), emphasising the subjective nature of this perception. They argue that additionally, for an experience to be classed as transitional, new behavioural responses are necessary. Hopson and Adams also argue that transitional events can take on a range of forms, effective at macro or micro levels. Transitions may be predictable or unpredictable, and people may encounter a transitional event voluntarily (for example, marriage) or involuntarily (for example, a partner’s death).

It is widely agreed that there are two major types of transitions people face: those linked to developmental stages or phases; and those associated with life events (Hopson, Scally & Stafford, 1992). Transition, thus, is also related to the areas of learning and education. While transition itself is widely accepted as a normal, human, experience, carrying an enormous potential for growth, it is also agreed that transitional periods are often accompanied by strong emotional experiences which are potentially uncomfortable and demanding (Hopson et al, 1992; Hussey, 2002; Viney, 1980).

Research on transition has been directed to transitions in education levels (Fournier & Payne, 1994; Johnson & Robson, 1999) and work roles (Hayes, 1976). Studies have focused on the experience of transition to parenthood (Belsky, 1985) and motherhood (Smith, 1994). As my review of some models of transition that follows

demonstrates, the centrality of meaning-making to transition is well recognised in the field. McAdams, Josselson and Lieblich (2001) state that: “meaning making lies at the heart of those turns in the road that people think of as life transitions.” (p. xv).

Hopson and Adams (1976) proposed a stage model of transition. Their model consists of seven stages: numbness; minimisation/denial; self-doubt/depression; acceptance of reality/letting go; testing; search for meaning; internalisation. They suggest that people do not move neatly between phases, or always complete all phases. The stage model proposed by Hopson and Adams is in some ways similar to Kübler-Ross’s stage model of grief (1975). Although these authors argue that their model of transition was developed to understand all types of transitions – major life changing events and changes in daily routines, surprise transitions and anticipated transitions – Hopson and Adams also argue that the model highlights the “potential for growth arising from any major disruption or calamity” (1976; p. 13). Hopson and Adam’s model places a person’s own meanings of the transitional experience centrally, consistent with personal construct ideas of transition.

Adams (1976) developed a descriptive model of the processes of transition (adaptation and growth) experienced when entering a new situation – specifically through qualitative investigation of intercultural experiences. The model is arranged by exploring feelings and reactions, concerns, coping activities and outcomes, across four periods of time. He called this a learning model. Adams (1976) asserted that an intercultural experience in itself does not lead to personal growth, suggesting, rather, that:

this process is stimulated by being immersed in the ‘differentness’ of the place and by struggling with the task of finding one’s way, by making the unfamiliar familiar, by risking to lead a choiceful rather than a choiceless life. When this is approached as an active learning task, rather than as a natural by-product, the rewards are at least commensurate with the effort. (p. 82).

Adams' model highlights the active nature of the person encountering transition. While Adams' does not offer a theoretical conceptualisation as a framework for his model, the position above is consistent with the constructivist, and personal construct position, that:

The organism is an active participant in its own experiences as well as learning.

We are ... co-constructors of the personal realities to and from which we respond.

Rather than just being a passive repository of sensory experience or a mechanical way station for information processing, the organism is portrayed as an active, anticipatory 'embodied theory.'

(Mahoney, 1991; p. 100).

Mahoney argues that this is one distinctive feature of constructivism. Adams' exploration of how personal growth may result, above, is reminiscent of a further feature of personal construct theory. As I showed in the previous chapter, Kelly adopts the analogy of person as scientist, and Walker, Oades, Caputi, Stevens and Crittenden (2000) argue that this metaphor needs to be understood in terms of potential, not actuality. In exploring this metaphor, and the centrality the process of confirmation/disconfirmation plays in the activities of the scientist, through the experience/validation cycle, they also suggest that, in addition, a process of non-validation is necessary to contrast with validation, capturing non-engagement in this cycle. That is, they suggest that sometimes people avoid (either deliberately or inadvertently) putting their hypotheses to the test of genuine experimentation, or ignore evidence that challenges their predictions. Adams' account, with the active, experiencing, person at its centre, raises issues consistent with both processes of validation and non-validation. Indeed, using these concepts, Adams is asserting that growth parallels with risking validation/invalidation by engaging in "making the unfamiliar familiar" and becoming immersed in "differentness", as opposed to opting not to experiment by engaging in non-validation processes.

Nicholson (1986) also proposes a model of the transition cycle. Nicholson's notion of the transition cycle states that there are four stages: preparation; encounter;

adjustment and stabilisation. Nicholson provides three propositions relating to this model. He argues that the cycle suggests perpetual motion: that is every person is at some stage (or multiple stages) in a transition cycle at any moment, and that the stabilisation phase of the cycle will lead to preparation for a new transition cycle. Secondly, Nicholson states that the processes and qualities of experiences at any stage of the cycle are different to those at other stages. Finally, Nicholson states that an implication of the cycle is that what occurs at one stage affects what happens at the next, and that experiences of each transition cycle in a person's life affect their next transition experience.

Viney (1980) offers a comprehensive personal construct account of transition in her study of women's experiences of change. Viney proposes a phasic model of transition, focusing on onset, mediating experiences, and outcome. Viney's model of transition is explicitly based on personal construct theory. While the model proposed accounts for the three phases of transition outlined above, it is mainly concerned with the mediating experiences of transition.

Viney (1980) argues that people are likely to experience an initial reaction to an ambiguous situation with feelings of uncertainty, anxiety and frustration. These reactions are as a result of realising that their systems of meaning are not able to assist them adequately in making sense out of this new, ambiguous situation. These initial reactions may take a range of forms, which become mediating experiences, contributing to the outcome of transition. These mediating experiences will vary according to the type of transitional event experienced. In addition to a range of emotional reactions, arising as a result of struggling with meaning change, Viney also outlines further mediating experiences focused on a sense of/lack of control, and peoples' perception of their social support. The final phase of Viney's (1980) model is the psychological cost of transition. It is suggested that people's flexibility in responding to their transitional experience will reflect psychological cost.



Other authors have explored transitional experiences empirically, without specifically developing a model of transition. Johnson and Robson (1999) conducted a longitudinal study using interviews and diary entries to qualitatively explore women's experiences of transition of entering higher education. Their analysis of these data resulted in an overarching theme of continuity and change. They found that the women in their study spoke and wrote about their various other roles (that is, other than their new student role), such as mother, wife and partner, friend or relative, and how these relate, impact on, and were impacted by, their new role as students. As well, the risk of being seen as different to people important to them was evident. Johnson and Robson argue that the transition to higher education can disrupt the continuities of life and identity.

In addition to this central theme, three further themes were discussed. Issues linked to ability formed the theme "Can I do it?"; "Do I belong" formed a theme relating to concerns about feeling part of the environment; and "Coping with transition" was a theme relating to how participants coped, and their views of what helped and hindered coping.

Johnson and Robson (1999) note the prevalence of expressions of anxiety, associated with the beginning of the programs, which is consistent with other research on transitional experiences. The authors suggest that these initial anxieties are related to the sense of unknown and unfamiliar, marking the situation. Johnson and Robson (1999) also discuss how the women coped with the transition, noting that over the period of the research, most participants appeared to become integrated into their program. They highlight the suggestion of reconstrual of the situation in comments such as "I'll keep an open mind" made by participants. They suggest that others used "deflection strategies" such as denial. They suggest that initial anxieties were lower for those prepared by having a realistic view of what would be involved, and suggest that advance contact with the university was seen as helpful, as well as particular aspects of the introductory phases of programs. Johnson and Robson argue that the creation of a sense of belonging and

reduction of feelings of difference were enhanced by a chance to discuss concerns in a 'safe' environment, and by perceiving other's as similar early on in the process. Again, readily prepared and structured interventions and exercises can be implemented to assist this. Other factors such as being organised, as well as practical support and assistance were seen as important in assisting coping with concerns regarding ability.

While Johnson and Robson (1999) do not use personal construct theory to conceptually frame their findings, and in fact they use Breakwell's theory of threatened identities, the themes outlined by these authors can readily be made sense of using personal construct theory. Using Viney's model of transition, Johnson and Robson's discussion of initial anxieties and uncertainties correlates directly to the Onset Phase of transition. The themes they describe of "Do I belong?" and "Can I do it" appear to be the different forms this initial anxiety and uncertainty took over time for the women experiencing this transition. These could be described as mediating experiences, and link also to perceived social support, a sense of personal competence and lack of personal control as well as emotional responses. The view of coping, and those helpful and hindering factors, described by Johnson and Robson, highlights: 1. the central role reconstrual plays in transition; and 2. the importance of experiencing sociality, which I described in Chapter 3, in an experience of transition.

Smith (1994; 1997) examined women's experiences of transition to motherhood, empirically exploring the notion of self-reconstruction. Smith collected data from four women visiting them four times, three during pregnancy and once five months after the birth of her child. Smith found that each woman actively reconstructed her self-concept as she went through the transition to motherhood, but that this reconstruction took various forms, which could be seen as producing a set of narratives about pregnancy. Smith's work highlights the active meaning making involved in negotiating transition, consistent with a personal construct account of transition.

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## Experiencing Work Transitions: Research Relating to Work Changes

As I have previously argued, one of the central features of becoming a Consumer Researcher (CR) is this job as a work role. The transition to employment increases the range of roles and status a person experiences (Hayes, 1976). For some of the CRs, it is likely that this work role is either a new experience, or a role to which they have returned after a break, and possibly limited previous exploration. Being in work has been linked to a variety of perceived benefits, such as: providing occupation and interest; feeling a sense of purpose; providing social contact; and contributing to self-esteem (Boardman, Grove, Perkins & Shepherd, 2003; Hayes, 1976; Harnois & Gabriel, 2000; Van Dongen, 1996). Work is both an important part of society and culture, and of individual people's lives, and meanings (Hayes, 1976; Harnois & Gabriel, 2000; Sharf, 2002). As I showed in Chapter 2, work holds multiple meanings for mental health consumers (Strong, 1997). Some of these meanings are directly related to the listed benefits above, as well as more specific meanings related to experiences of using mental health services, and living with a diagnosis of mental illness.

Having meaningful employment is believed to be particularly important to the recovery process (Strong, 1997). From her findings, Strong suggests that work is meaningful:

when it fits with the person's values, beliefs, interests, goals, sense of self, and relationship with illness. Therefore, meaningful tasks and activities not only engage a person's time and energy, but also engage the person by forming a connecting bond. (Strong, 1997, p. 37).

A-priori, the nature of working as 'consumer researchers' for people who are experienced using mental health services should be highly meaningful.

The World Health Organisation suggests that employment provides five categories of psychological experience that promote mental well-being, which include:

time structure; social contact; collective effort and purpose; social identity; and regular activity (Harnois & Gabriel, 2000). In addition, the WHO notes that there are also likely to be stressful characteristics of work (Harnois & Gabriel, 2000). The importance of the workplace being respectful and positive, with clear support and supervision for consumers are identified as keys to success in workplace entry, or re-entry (Bond, 1998; Harnois & Gabriel, 2000; Sane Australia, 2003<sup>a</sup>; Xie, Dain, Becker & Drake, 1997).

Despite widespread recognition of the importance of the work role in people's lives, there is no clear description of the experience of transition for consumers, of entering or re-entering the workforce available in the literature. Similarly, no model or description of the transition from consumer to consumer research can be located. The area of career and work transition or development, have, however, been extensively explored. McAuliffe (1993, p. 23) argues that:

career development ...[has] been increasingly characterised in recent decades as a lifelong series of choices that individuals make to express their changing needs.

This dynamic understanding of career has replaced the static conception that had been a legacy of the trait-factor-dominated counseling approach.

McAuliffe further suggests that "career can be considered to be an act of meaning construction." (p. 23). This perspective on career development supports the approach to understanding consumers' experiences of becoming researchers from a phenomenological and personal construct approach, which explores the personally and relationally constructed meanings of this transition by consumers.

Morgan and Foster (1999) describe two feminist models for career counseling with women re-entering the workforce after child-birth, which they argue combined can become "a viable cognitive developmental model of career counselling." (p. 131). The first model described is Christian and Wilson's (1985, cited in Morgan & Foster, 1999) three-stage model, which includes a stabilisation stage, personal growth stage, and action phase. The second model is Blocher and Siegal's (1981, cited in Morgan & Foster, 1999),

which proposes the necessary conditions for cognitive developmental change within the career counseling context as: involvement; challenge, support and structure; and feedback, application and integration. Morgan and Foster (1999) argue that Blocher and Siegal model parallels each stage of Christian and Wilson's model, with their feedback, application and integration phase extending the focus of Christian and Wilson's third stage. Morgan and Foster argue that this model enables the career counselor to assist their client to move along the developmental hierarchy.

Neimeyer and colleagues (Neimeyer, 1988; Nevill, Neimeyer, Probert & Fukuyama, 1986; Sharf, 2002) have developed a four-stage model of development of vocational constructs. This model attempts to combine concepts of cognitive integration and differentiation into a framework for understanding the development of vocational structures, using Super's understanding of vocational development as the "process of growth and learning which underlies the sequence of vocational behaviour" (1957, cited in Neimeyer, 1988, p. 455). According to this model, vocational development represents an ongoing reorganisation of the structural characteristics of the meanings used in anticipating and understanding work. The model is based then on the assumption that structural features of systems of meaning actually change based on experience, in a developmental progression. In the first stage of the model, people will have poorly integrated and differentiated systems – the least developmentally advanced. The mediating stages represent increased organisation (integration) of the system; and increased discrimination of dimensions for vocational judgment (differentiation). Over the course of experience, these dimensions are integrated into an increasingly complex meaning system for anticipating and interpreting occupational information. Neimeyer, Nevill, Probert and Fukuyama (1985; Neimeyer, 1988; Nevill, Neimeyer, Probert & Fukuyama, 1986) argue that this state of high integration and high differentiation is assumed to be the most developmentally advanced stage.

This model demonstrates the application of personal construct theory in the area of understanding careers, and importantly, also adopts a developmental approach which is consistent with the transitional interpretation I am taking. The model does not provide much direction for understanding what the experience of work transition is like for the person in transition, because it focuses on the development of vocational constructs, however, the structural focus is an important contribution. The concepts of cognitive integration and differentiation together provide a useful framework for considering general changes of meanings, or growth and learning that occurs during work transitions, not just vocational construct change. The model indicates that over the course of experience, increased integration and differentiation of the meaning system will result in an increasingly complex system for anticipating and interpreting oneself and the world generally (or specifically, depending on the type of work experiences). For the consumer researchers, this means that as they have continuing experiences as consumer researchers (which include experiences with services, other consumers, with academics, with the university) not only will their vocational constructs become increasingly complex, but so will their broader construing system.

It appears there is only a limited range of studies examining specific experiences of transition or change in work. While there is some literature describing and exploring the nature of work and job transition, most of the literature in this field takes a career perspective, which involves a life-span focus (Conyers, Kock & Szymanski, 1998; Sterrett, 1999), or consideration of more long-term phases in career development (Guest, 2000; Noonan, Gallor, Hensler-McGinnis, Fassinger, Wang & Goodman, 2004). The transitions of entering or re-entering the work force are categorised as normative transitions with other work transitions such as changing work roles within an organisation, changing professions, or moving organisations (Sharf, 2002). Normative transitions are typically considered non-problematic, particularly if anticipated, and so much more research within the career literature can be found focusing on non-normative

transitions and unexpected normative transitions such as unanticipated job loss (Sharf, 2002). There are few studies describing and exploring the nature of specific work transitions from a personal vantage point. This lack is reflected in criticisms of the theories and models underlying career counseling, which argue that these fail to focus on personal experience, and that career counseling must shift to more “meaning-centred” models that emphasise client’s meanings and experience (Morgan & Foster, 1999). In fact, in 1997, Savickas argued that career counseling literature demonstrated an embryonic shift from being “an objective enterprise to an interpretive science.” (1997, p. 150).

Nicholson (1986) specifically considered work role transitions using his conceptualisation of the transition cycle described earlier in this chapter. Nicholson suggests that career can be conceived as “chained sequences” of transition cycles (p. 259). He proposes nine dimensions along which transition cycles can be characterised, which include: the speed of the cycles; amplitude, or the level of novelty it poses for the people experiencing it; symmetry, or the spread of time in each phase of a cycle; continuity of phases and cycles; discretion, or the level of control a person holds themselves over their own transition cycles compared to environmental pressures; complexity of the transition cycle; propulsion, or who initiates the transition; facilitation, or support available through the cycle of transition; and finally the significance of the outcomes of transition. Nicholson suggests that each of these properties of the transition cycle affect how the transition is experienced and what the outcomes of the transition are. What Nicholson provides is clear focus on the importance of understanding work role transitions, not just whole careers, and a phasal proposition of the structure of work role transitions.

Fournier and Payne (1994) explored changes in self construction during the transition from university to employment, using personal construct theory as a framework. These authors adopted this theoretical approach because, they argued, it

provides a powerful framework to explore transition, given the centrality of creating and re-creating personal meanings to the theory. Methodologically, these authors also argue, the idiographic approach personal construct theory brings is necessary to study experiences of transition. What their study reveals about work transitions, specifically the move from university to work, was that this transition led to changes in the way participants viewed themselves: that is their self-constructions. Fournier and Payne argued that these changes in self-construction were qualitative, rather than simply quantitative. The implication of this is that new self-constructions were formed, rather than only movement between poles of a construction occurring, evidence of increasingly differentiated construct systems. Fournier and Payne conceptualise these changes in self-construing as related to the new social environment, and the new possibilities this provides for invalidation of old constructions of self. Additionally, they found some evidence that this change in self construing was at core identity level. Fourier and Payne also argue that their findings reveal the importance of individual differences in the nature of change experienced, as they found diverse changes between different participants having occurred.

McCall (1988) has examined growth or development from on-the-job experiences, for executives. McCall describes the empirical identification of 16 types of experiences or 'key events' that are seen as developmental opportunities. These fall into four categories including: 1. assignments; 2. other people; 3. hardships; and 4. other events. McCall notes that challenge underlies the description of development in this context. It seems that within career or work roles, development often occurs for a person when they face difficulty and challenge. Meeting the challenges faced "left little choice but to learn and develop new abilities." (p. 5). Executives that McCall reports data from regarding development and change, indicate that the degree to which situations were new and unexpected also contributed to the development that they described. "From the feeling of being overwhelmed, they developed the ability to adapt." (McCall, 1988, p. 5).



Experiences of transition also link to educational experiences. Quinlan and O’Brodivich (1996) note the connection of adult learning, career transition and life transition, stating: “for many adults, further education often represents a stepping stone from one life transition to another...” (p. 174). These authors explore the role of educational institutions in supporting personal transitions in this context, stating that: “Educators need to understand that support should enhance learners’ capacity to act as change agents on their own behalf” (p. 175).

Other researchers have examined highly unique work transitions, for example army personnel in the United States returning to civilian jobs (Gowan, Solesbee Craft, & Zimmerman, 2000) and United States Olympic athletes’ transitions from their sporting careers to alternate workplaces (Ungerleider, 1997). The major theme is Ungerleider’s (1997) findings, which were based on interview data with 57 ex-athletes, was the important role of support. Other authors also describe the centrality of support in work transitions (Quinlan & O’Brodivich, 1996).

### Conclusions

In this chapter I have discussed the context of human change, as the background for developing the model of mental health consumers becoming researchers. This included describing understandings of transition, elaborating the understanding personal construct theory offers, through describing Viney’s model of transition (1980). The remainder of the chapter was devoted to a further understanding of work transitions, given the centrality of the work role in Consumer Researchers’ experiences with the Consumer Evaluation of Mental Health Services (CEO-MHS) project. Neimeyer et al’s (Neimeyer, 1988; Nevill et al, 1986) model of development of vocational constructs, I argued, can be usefully applied as a framework to understanding the structural change that occurs during work transition.

The career counseling literature highlights the limited exploration of personal meanings and experience that has featured in theories and models guiding the field, and authors in the field have argued that a shift to more subjective understandings is necessary. While a career focus has dominated the literature relating to transition in adult working life, there is a small number of studies reviewed here that focus specifically on work or job role transitions. While viewed within this body of literature as a normative transition, these studies indicate that some important factors in experiencing the transition of entering or re-entering the workforce include: support; challenge and the feeling of being overwhelmed; and the possibility of change at core identity level. Adult education can act as a fulcrum to transition.

## CHAPTER 5

### APPROACHES TO HEARING AND UNDERSTANDING CONSUMERS' EXPERIENCES: EXPLORING RESEARCH PARADIGMS AND QUALITATIVE METHODS

In this chapter, I set out the reasons for my choice of qualitative methodology to conduct this research, and look at the interlinked meta-theoretical and methodological issues and implications that informed my choice. I have argued in earlier chapters that theoretical and methodological alternatives to the medical model are needed to conduct research with mental health consumers, a view also supported by other researchers (Hostick & McClelland, 2000). In Chapter 3, I presented the meta-theoretical underpinnings of this research, and in Chapter 4, the importance of people's meanings in life transitions was highlighted. In this chapter, I expand this stance further to explore alternatives to quantitative, positivist, research approaches and by the end of the chapter turn to specifically focus on research methodology. While a methodology is a tool, a choice of method also carries epistemological, ontological, and value commitments (DeCruz, 2001; Guba & Lincoln, 1994; Nagy & Viney, 1994; Woolgar, 1996). I will examine the links between personal construct theory and qualitative methodology, particularly focusing on the links between personal construct theory and phenomenology, narrative approaches and participatory research paradigms. In the final section of this chapter, I will examine the issue of determining the quality of qualitative research, and present a set of criteria that can guide an evaluation of qualitative research reporting; in later chapters I use this guide to appraise the research I present in this document.

### Quantitative and Qualitative Research and Research Paradigms

Scientists are not engaged merely in the passive description of pre-existing facts about the world, but are engaged in actively formulating or constructing the character of the world. (Woolgar, 1996, p. 15).

Qualitative methods in psychology are generally linked with an alternative to the dominant, traditional, received view of science (Woolgar, 1996). In his exploration of qualitative methods and the ideas of science, Woolgar (1996) highlights that what have been seen as the central characteristics of science have varied over time. He also

highlights how highly dependent decisions made are, in any research study, on “local conditions, circumstances and opportunities” (p. 15). These issues, he argues, indicate that scientific activity is “constructive” not “descriptive of facts”. Similarly, Guba and Lincoln (1994) outline a range of critiques of the received view of science that have been expressed. Guba and Lincoln (1994) suggest that extraparadigm critiques provide the most serious challenge to the received view, as alternative paradigms bring into question the basic assumptions guiding inquiry. Supporting Woolgar’s argument, they identify the following issues:

1. the theory-ladenness of facts. They highlight that “facts” are only considered to be such within some theoretical frameworks, which means that theories and facts are interdependent;
2. the underdetermination of theory (otherwise known as the problem of induction) which calls into question the historical proposition of science that it can, by its methods, converge on “the” truth;
3. the value-ladenness of facts. They argue that theories can be seen as value statements, so not only are facts interdependent with theory, but values as well. A value-free posture, fundamental to the received view of science, is therefore compromised; and
4. the interactive nature of the researcher-participant relationship.

Guba and Lincoln (1994) also discuss a range of intraparadigm critiques, which they argue expose many inherent problems of the received view. The possible problems they indicate as inherent to the received view of science include: context stripping; exclusion of meaning and purpose; disjunction of “grand theories” from local contexts and theories; inapplicability of general data to individual cases; and “exclusion of the discovery dimension in inquiry” (p. 106).

In general, qualitative research is primarily concerned with meaning and understanding, as opposed to prediction and control, as in a quantitative approach (Guba & Lincoln, 1994; Lyons, 1999). Using qualitative methods, questions can be asked about

personal meaning and context (Lyons, 1999). Qualitative methodology is traditionally linked to interpretative and critical research paradigms, rather than positivism (Fossey, Harvey, McDermott & Davidson, 2002). It is for these reasons that I chose to adopt qualitative methods to conduct this inquiry: my research questions are directed towards understanding consumers' personal experiences and meanings, and my metatheoretical stance, based in personal construct theory, requires methodology that fits interpretative paradigms. However, while making broad assertions about qualitative methodology, and its meanings, it is important to note that a range of qualitative methodologies exist, each carrying slightly different epistemological, ontological and value commitments.

Hayes (1997) argues that, while “quantitative versus qualitative” is often used as a straightforward dichotomy, the distinction is actually not so clear. Indeed, she suggests that a range of component meanings are linked to the distinction and all are better considered as continuums, rather than as dichotomies. Hayes (1997) discusses seven component meanings, previously identified by Hammersley, which include: qualitative versus quantitative data; natural versus artificial settings; focus on meanings rather than behaviour; adoption or rejection of natural science as a model; an inductive versus a deductive approach; identifying cultural patterns versus seeking scientific laws; and finally idealism versus realism.

At this broad level of understanding, qualitative rather than quantitative methods provide me with the tools I need to explore the experiences of consumers becoming evaluation researchers, and as I argued in Chapter 3, alternatives to positivist assumptions and methods are needed for my work with mental health consumers. I will now explore in closer detail personal construct theory and the specific approaches to qualitative methodology that have informed my research approach.

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## Personal Construct Theory and Qualitative Methodology

In Chapter 3, I argued that a constructivist paradigm broadly, and personal construct theory specifically, forms the underpinning epistemological and meta-theoretical position for this research. In that chapter, I indicated that the assumptions underlying personal construct theory contrast to those made by the medical model, and the associated positivist view of science. Specifically, I argued that my approach to this research needs to:

- acknowledge consumers as construing people;
- hear and honour consumers' views and experiences;
- ensure consumers an active role, providing opportunities for empowerment;
- consider social and cultural contexts; and
- acknowledge mutual expertise within relationships (specifically researcher-consumer in this case).

The methodology chosen for the studies presented in the following chapters is based on this position, and qualitative approaches have been chosen because of the fit between these approaches and the requirements I held, stated above. In the remainder of this chapter, I will focus on a discussion of the qualitative research approaches that inform the development of the model of mental health consumers becoming evaluation researchers, because they meet the requirements I set out in Chapter 3, summarised above. In addition, I will show how the methods and approaches to the research chosen are consistent with the meta-theoretical stance I have outlined, as informed by personal construct theory.

### *Personal Construct Theory and Phenomenology*

Phenomenology ... is not a rigid school or uniform philosophic discipline. There is great diversity in the points of view of thinkers who could be classified under the general rubric *phenomenology* and the most proper description of this way of

approaching philosophy is the phenomenological “movement”... The diversity of points of view held by philosophers working within the phenomenological tradition makes a summary of major phenomenological tenets difficult....

(Stewart and Mickunas, 1974)

Van Manen (2002) defines phenomenology as being “the study of phenomena, the way things appear to us in experience or consciousness.” He argues that:

“Phenomenology aims at gaining a deeper understanding of the nature or meaning of our everyday experiences.” (van Manen, 1990. p. 9). While the term phenomenology had been used by Kant and Hegel, most authors agree that phenomenology as a movement developed with Husserl, however, is not synonymous with Husserl, as a range of comprehensive contributions have been made (Moran & Mooney, 2002; Spiegelberg, 1975; van Manen, 2002). Van Manen (2002) outlines a range of orientations within phenomenology including existential, transcendental, hermeneutical, linguistical and ethical phenomenology. He also distinguishes phenomenology of practice. Van Manen does, however, argue that “there exist many continuities and discontinuities among the various phenomenological orientations or movements.” Van Manen suggests that what distinguishes phenomenology of practice is less an interest in the philosophy of phenomenology, and more a focus on its practice and application to domains of human science.

While Kelly (1955/1991) himself asserted that personal construct theory is not phenomenology, the many connections and parallels between personal construct theory and phenomenology have been elaborated by others (Apelgren, 2003; Butt, 1997 & 2003; Chiari & Nuzzo, 2000; Viney, 1988; Warren, 1985, 1990, 1991). As Apelgren (2003) outlined, proponents of personal construct theory and phenomenology share similar ontologies. Personal construct theory is particularly resonant with existential and hermeneutic phenomenological philosophy (Butt, 1997; Chiari & Nuzzo, 2003; Warren,



1998). Apelgren argues that when adopting a constructivist meta-theory, use of phenomenological methods for data collection and analysis is possible.

Davidson (2004), after Husserl and Mohanty, discusses the need to move toward a “phenomenology of respect” as opposed to a “phenomenology of suspicion” in working with people experiencing psychological distress. Davidson, Staeheli, Stayner and Sells (2004) argue that early phenomenological approaches to psychopathology, while important in producing an alternative to other frameworks adopted at the time: “remained primarily models of disease, disorder, and dysfunction, allowing little to no room for improvements or recovery.” Central to their argument is concern regarding a continuation of the “expert” and “patient” roles in the early phenomenological work conducted in the field and the implications of these that I discussed in Chapter 3 relating to the medical model and psychodynamic approaches to mental health and illness. I argue that personal construct theory sits congruently with a “phenomenology of respect” and draw particular attention to the underpinning philosophy of constructive alternativism and the social nature of construing (Kelly, 1955/1991; Landfield & Leitner, 1980; Walker, 1996). Personal construct theory demands that the personal world of the researcher *is not taken* to be a proxy, either implicitly or explicitly, for “the” world. As Chiari and Nuzzo (2000) argue, from the view of personal construct theory, a psychotherapeutic interaction attempts to foster “further meanings” both in the therapist and the client, not more “correct” or “better” interpretations of the client. They argue that therapy from this perspective, will result in a change: “in which both of them do not remain what they were” (p. 96). This is also applicable to research interactions.

Van Manen suggests that phenomenological methodology involves radical reflection, comprised of two components: “reductio” and “vocation”. The aim of the reductio, he describes as: “to reachieve direct contact with the world by suspending prejudgements, bracketing assumptions, deconstructing claims, and restoring openness”, and of vocation to: “let things “speak” or be “heard” by bringing them into nearness

through the vocative power of language”. Van Manen describes a range of empirical methods, which are used to explore examples and varieties of lived experience through accounts of some form. Empirical methods include: interviewing, observing, writing and describing. He also outlines reflective methods, whose purpose is to “grasp the meaning of something” and may include: hermeneutic interview reflection; thematic reflection; or collaborative reflection.

In the studies described in the following chapters, which outline the development of the model of the experience of consumers becoming researchers, phenomenological approaches to data collection and analysis have been adopted. The methods used are discussed in more detail later in this chapter, and are described in full in Chapters 7 and 10.

### *Personal Construct Theory and Narrative Approaches*

According to McAdams et al (2001), narrative epistemologies emphasise: “qualitative over quantitative research, hermeneutic over logical-positivistic frames, idiographic over nomothetic points of view, and indicative over hypothetico-deductive strategies of inquiry” and encompass a wide set of approaches: case studies; life histories; content analysis of life accounts; discourse analysis; ethnographies; psychobiography and biographical approaches (McAdams et al, 2001). From a narrative perspective, meaning is constructed through social discourse, rather than being considered inherent in an act or experience. Bruner (1986) argues that narrative modes of knowing privilege the particulars of lived experience. Methods of data collection in this approach seek to create contexts where stories can be told and jointly understood (McAdams et al, 2001).

Several personal construct authors have argued that personal construct theory readily aligns with narrative approaches (Botella & Herrero, 2000; Chiari & Nuzzo, 2003; Mair 1988; Mancuso, 1996): Chiari and Nuzzo (2003) suggest that Kelly’s assumption of constructive alternativism implies many of the features of a narrative approach. Central to

the two perspectives is emphasis on meaningfully understanding the world, which is viewed as interpretative action (Botella & Herrero, 2000).

The data collection methods, as described in Chapters 7 and 10 have been informed by personal construct theory, and also fit within a narrative perspective. Polkinghorne (1988) defines the term narrative as a “kind of organizational scheme expressed in story form... ‘Narrative’ can refer to the process of making a story, to the cognitive scheme of the story, or the result of the process – also called ‘stories,’ ‘tales,’ or ‘histories.’” (p. 13), as opposed to the more everyday use of the term narrative as: “a spoken or written presentation” (p. 13). While the narrative structure of the data is not my focus in analysis, I have sought narratives, through interviews and focus groups in Study 1, and with the use of additional methods of self-characterisation and winding river charts (see Chapter 10 for a description of these methods) in Study 2. Chiari and Nuzzo (2003) argue that the self characterisation methodology “is perfectly in line with the narrative approach and qualitative analysis of personal experience.” (p. 47).

### *Personal Construct Theory and Participatory Research Paradigms*

Another important conceptual basis of this research is action research, and participatory action research. Similar to the area of qualitative methods and phenomenology, there are a range of research approaches that fall within the category of participatory research, each with different emphases (Taylor et al, 2002): for example, emphasising the political, in the case of Participatory Action Research (PAR), or the psychological, in the case of Co-operative Inquiry, to be described shortly. Reason argues, however, that these approaches stand together in “marked contrast to orthodox social research” (1994, p. 332) holding common epistemological positions. While each approach draws from different theoretical bases, there is convergence on the epistemological position that “knowledge arises in and for action” (Reason, 1994, p. 333): that is, participatory research paradigms emphasise “the fundamental importance of

experiential knowledge.” (Reason, 1994, p. 333). Coupled with this concept, is the idea that this experiential knowing arises through interaction, or participation, with others.

Whyte, Greenwood and Lazes (1991, p. 20) define participatory action research (PAR) saying, in PAR: “some of the people in the organisation or community under study participate actively with the professional researcher throughout the research process from the initial design to the final presentation of results and discussion of their action implications.” They note the sharp contrast between PAR and traditional models of ‘scientific research’ challenging the traditional dichotomies of ‘expert’ and ‘passive subject’. According to these authors, PAR is centrally about engagement with the world.

Boog (2003) described four recent action research approaches that have been strong in the last two decades. These included: pragmatic action research; co-operative inquiry (which Boog suggests carries an wholistic –spiritualistic worldview); critical action research (which according to Boog is grounded in critical hermeneutics and neo-Marxist theory); and finally, action research based in systems thinking. Boog suggests that while there are clearly differences between the various approaches, there is increasingly greater convergence. He outlined six areas where he notes strong unity:

1. cycles of research, experiential learning and action;
2. a common goal-orientedness and ‘ethics’: emancipation, individual and social empowerment and participatory democracy;
3. the meta-theoretical stance of ‘person as active creator of their world” which moves beyond traditional dualisms;
4. the underlying action theories imply knowledge in social research is gained through mutual understanding – or double hermeneutical circles;
5. validation is achieved through processes of communication or dialogical validity; and
6. each involves individual and communal reflection on the research process.

The consistency between these areas of convergence for action research approaches outlined by Boog, and the theory of personal constructs, conveyed in Chapter 3, is also

striking. Pope and Denicolo (1991) have previously examined the shared assumptions of personal construct theory and action research, also noting strong metatheoretical commonalities.

While I have not adopted any specific action research or participatory action research approach in this research, the general principles guiding the development of the model of mental health consumers becoming researchers, as well as the broader research study within which this is occurring, are strongly consistent with those of participatory, and action research approaches more collectively. Action research requires that researchers are involved in creating change as well as generating knowledge, and participatory action research, an extension of action research, has its roots in involving “oppressed” people in critical analysis and action to change their situations (Nelson, Ochocka, Griffin & Lord, 1998). Consumers of mental health services have been involved in the broader Consumer Evaluation of Mental Health Services (CEO-MHS) project from design through data collection, interpretation and dissemination of results, with a research aim of developing a consumer directed method of evaluating mental health services. In this research, consumers have been involved with me in reflecting on, and understanding, what this experience of “becoming” and “being” a researcher has meant for them. Like personal construct theory, action research views the relationship between participants and researchers as one of “co-operative” enquiry, acknowledging the differing perspectives of people within any research enterprise.

#### Approaching Data Collection and Analysis within this Framework

As I have stated earlier in this Chapter, I needed an approach to working with the consumers involved in this research, of collecting data with them, and understanding their stories and experiences which allowed me to:

- acknowledge consumers as construing people;
- hear and honour their views and experiences;

- ensure them an active role, providing opportunities for empowerment;
- consider social and cultural contexts; and
- acknowledge and work with the mutual expertise within our relationships.

As the discussion above indicates, I have conceptualised this research as being both phenomenological, and participatory, within a meta-theory defined by personal construct theory.

The Mutual Orientation Model of Data Collection, as described by Viney (1987; 1988) proposes an approach to data collection that is highly consistent with personal construct theory, phenomenological approaches, as well as participatory research. Viney (1988) states that this model is applied: “when both the data collector and the informant contribute something to, and gain something from, the data collection. Their actions are influenced by both their private interpretations and by what takes place publicly between them” (p. 375). Viney argues that in this model of data collection, five stages of interaction take place between the data collector and participant, which reflect iterative loops starting with a request by the data collector and ending with confirmation or disconfirmation of their interpretations by the participant.

The data collection approaches used in Study 1 and Study 2 vary to address the differing research questions appropriately. Both, however, use a range of qualitative, phenomenological and participatory approaches to data collection and interpretation and understanding of meaning. In both studies interview and focus group approaches are used. Interviews provided opportunities for insight into participants’ personal meanings and interpretations in both studies, while focus groups allowed for group construction and understanding. Authors such as Kitzinger (1995), Sim (1998), and Phan and Fitzgerald (1996) advocate that focus groups particularly are a strong method to help ensure that research is being conducted from participants’ perspectives. A variety of techniques were used in interviews during Study 2, which I will describe in more detail in Chapter 10. A

range of reflective methods were also adopted, including thematic analysis, using Interpretative Phenomenological Analysis, as described by Smith, Jarman & Osborn (1999), as well as what van Manen (2002) described as hermeneutical interviewing, or collective interpretation of meaning, and understanding of experience. As participatory research mandates, the consumers whose experience this research aims to understand, were involved throughout each phase in describing, generating, and interpreting meanings of their experiences.

### Determining the Quality of Qualitative Research

In the final section of this chapter, I will review a range of positions relating to determining the quality of qualitative research. Debate about how to evaluate their research has been strong between qualitative researchers and the result has seen a number of different sets of criteria developed. As my review below indicates, there has been a growing move toward understanding and judging qualitative research in a manner distinct from understandings of rigor in quantitative research, with a strong focus on matching evaluative criteria to the specific epistemological and metatheoretical position of the enquiry. For this reason, towards the end of this section, I have reviewed in depth Manning's (1997) elaboration of the concept of authenticity, as it relates specifically to constructivist enquiry. I conclude by summarising a set of criteria outlined by Fossey et al (2002) which synthesise criteria at the core of debates over the last decades, and which are highly consistent with a constructivist epistemology.

Miles and Huberman (1994) identify five main issues in determining the quality of qualitative research. These relate closely to indicators of quality used to measure quantitative research (Patton, 1990), and include: objectivity/confirmability; internal validity/credibility/authenticity; reliability/dependability/auditability; external validity/transferability/fittingness; and utilisation/application/action.

Nagy and Viney (1994) also argue that “established criteria exist that can be applied to qualitative methods to demonstrate their rigorous application”. These authors highlight a set of four criteria originally identified by Lincoln and Guba (1985) within the overall category of trustworthiness. The criteria “parallel those used in positivism, but are more appropriate to the aims of interpretative research. These are credibility (ie. internal validity), transferability (external validity), dependability (reliability) and confirmability (objectivity).”

Other authors, however, argue that there is a need for qualitative research to move away from use of modified or parallel indicators of quality from quantitative methods, because of the differences in epistemological assumptions (Brydon-Miller & Tolman, 1997; Fossey et al, 2002; Guba & Lincoln, 1994; Higgs, 2001; Manning, 1997; Seale, 1999; Willig, 2001). Indeed, these authors argue that it is problematic for qualitative researchers to attempt to use these types of quality indicators, and rather, that quality indicators more consistent with the philosophical stance and aims of qualitative research should be adopted (Fossey et al, 2002; Lyons, 1999; Willig, 2001). Brydon-Miller and Tolman (1997) highlighted the challenge facing the qualitative research community in defining standards regarding the rigour and quality of this research. These authors recognise that the currently accepted criteria for establishing quality in psychology are not appropriate for qualitative approaches. As Brydon-Miller and Tolman (1997) note, the challenge of “how to evaluate our data in the context of acknowledging multiple, equally valid perspectives on the phenomena” has been a lively debate for a number of years.

Lyons (1999) argues that a variety of criteria for evaluation of qualitative research are necessary, because of the range of paradigms reflected in this area. Lyons states that: “effective evaluation of qualitative research requires explicit consideration of ontological, epistemological and methodological issues” (1999, p. 247).

Manning (1997) argues that two sets of criteria exist to address quality in constructivist enquiry: trustworthiness and authenticity. Trustworthiness, she argues, was



conceived as parallel to empiricist concepts while authenticity emerged from the constructivist paradigm without a positivist parallel. Manning (1997) provides a discussion on the set of choices researchers need to consider, to achieve authenticity, her work as others above, an extension of the foundations Guba and Lincoln laid in the mid to late 1980s. Manning (1997) is clear that the set of choices she proposes should not be viewed as a checklist to be applied in a prescriptive approach, but rather be viewed as strategic suggestions, each requiring deliberation from the standpoint of the particular context and setting in which the research is undertaken, and considerations of authenticity are intimately linked to ones metatheoretical position, just as methodological considerations are. Manning indicates five types of authenticity based on a constructivist epistemology, and dimensions which could be considered for each:

1. Fairness is the first type of authenticity. This implies an attempt to achieve a balanced view that presents the range of constructions and the values underlying them in the interpretation. To achieve fairness, a researcher engages in the task of trying to ensure that participants have an equal opportunity to voice in the research. Using direct quotes can be one powerful method of achieving fairness. Considerations of fairness also include informed consent; member checking – or engaging in the collaborative process of negotiated outcomes, and of the researcher being accountable to the people who participate; prolonged engagement; and persistent observation. Reflexivity is the other key consideration that Manning includes within fairness. She describes reflexivity as making explicit the researchers' perspectives. The final key consideration included within fairness is peer debriefing, which allows others knowledgeable about research methodology to provide alternative explanations and hypotheses, challenging habitual ways of thinking.
2. Ontological Authenticity. This category of authenticity, according to Manning (1997) addresses the question: "Did the experience of the research process improve the respondents' conscious experiencing of the world?" Manning proposes several

considerations related to ontological authenticity. The first is dialogical conversations – rather than ‘one-way’ information gathering sessions between researcher and respondent. In dialogical conversations, Manning (1997) states, respondent’s meanings unfold, in collaboration with the researcher. The second consideration relates to who owns the data and how the use of data is chosen, which Manning calls ‘Openness of purpose’. She describes this dimension of authenticity as engaging in efforts “not to foreclose too soon on the inquiry purposes”. This reflects the joint nature of constructivist research, where respondents and researcher should guide the purpose and meanings that emerge. Taking an emic perspective is the third consideration Manning includes within ontological authenticity. From an emic perspective, the researchers’ role is to discover and interpret meaning from the participant’s point of view, rather than their own viewpoint, while acknowledging that this is always an approximation, an interpretation. The final dimension of ontological authenticity Manning outlines is a caring and trustful researcher-respondent relationship, which she stresses, involves considerable time and attention, ensuring that the researchers’ goals are clearly explained, and ethical issues discussed in full.

3. Educative authenticity is the third type of authenticity Manning describes. She states that this authenticity type addresses the question: “did the experience of the research process broaden the respondent’s understanding not only of himself or herself (i.e. ontological authenticity), but of the expressed constructions of other participants?” Educative authenticity involves participants gaining increased awareness of others, and Manning describes considerations relating to educative authenticity as including member checking, explication of the researcher’s assumptions and conducting internal audits. Internal auditing involves gaining the perspective of participants or other key stakeholders on well-developed drafts of the research reports, allowing clarifications and refinement of the themes that arose and interpretations the researcher has made.

4. Catalytic authenticity, as described by Manning, involves the necessity for pragmatic purpose to research results, ideally results should stimulate action: at a minimum, the results must be worthwhile to those who participated. Considerations relating to catalytic authenticity involve joint construction of interpretation, accessibility of the reports/product of the inquiry, as well as the possibility that results could be used for practical purposes – which means the research must be sufficiently related to the context and participants’ meanings that the conclusions are meaningful to stakeholders.

5. Tactical authenticity is the fifth type of authenticity elaborated by Manning, and refers to whether participants are empowered to act on the findings as a result of the research process. Manning suggests that approaches to research that involve co-researcher relationships with participants, rather than researcher/object relationships provide opportunities for empowerment, rather than abuse of power. In addition to a number of considerations included as helpful to other types of authenticity, Manning suggests that negotiated use of data and outcomes, and efforts to maintain strong participant and site confidentiality are further issues closely related to achieving tactical authenticity.

Fossey et al (2002) synthesise the key issues in evaluating the quality of qualitative research, bringing ten issues within two broad categories:

- 1) Methodological rigour
  - a) Congruence: between methodology used and research issue; between methods and methodology.
  - b) Responsiveness to social context: adaptation of research design to real-life setting/context of the research; engagement with participants.
  - c) Appropriateness: for example, of sampling strategies and data collection methods.
  - d) Adequacy: for example, of sampling breadth and depth; of description of data collection methods; iterative nature of analysis; of report.

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- e) Transparency: of methods, and analysis
  - 2) Interpretative rigour
    - f) Authenticity: in presentation of findings and interpretations, eg: Are participants' voices represented through quotes? Are there a range of voices and views? Would descriptions and interpretations of data be recognisable to those having the experience? Were participants involved in checking or conducting interpretation?
    - g) Coherence: in presentation of findings and interpretations. Do the findings 'fit' the data from which they were derived? Have multiple researcher perspectives been incorporated?
    - h) Reciprocity: for example, to what extent were processes of conducting and reviewing the analysis shared with participants? Were participants involved in presenting the study?
    - i) Typicality: what claims are made for generalisability? Is an adequate description provided for readers to evaluate the applicability of findings to other settings?
    - j) Permeability of the researcher's intentions, engagement, and interpretations: for example, is the researchers' role transparent in the interpretative process? Are the researchers' intentions and values clear in the report?

These key issues in evaluating qualitative research synthesised by Fossey et al (2002) focus more on what could be expected to be found in a research report indicating that quality research has been conducted, whereas Manning's elaboration of authenticity remains more oriented towards the research process and approach. The two are however highly complementary: the criteria summarised by Fossey et al (2002) are consistent with Manning's discussion of authenticity and quality research based within constructivist epistemology.

Whyte et al (1991) also outline the need for alternate definitions of rigour to those offered by positivism, outlining three criteria which they suggest are particularly relevant to judging PAR. These are closely reflective of those outlined above. Fossey et al (2002)

argue that while extensive, the criteria they have summarised should not be considered exhaustive, and that this set of criteria should be adopted as a guide, not a checklist. They state that each criterion will hold differing relevance and importance, depending on the overall context and purpose, as well as research paradigm guiding the research, which resonates with Lyons' and Manning's views of judging the quality of qualitative inquiries. I will make use of Manning's (1997) guide to assess the quality of my research, as presented in Study 1 and Study 2, in the final chapter of this thesis.

### Conclusions

In earlier chapters, I have outlined the meta-theoretical position of personal construct theory, as the basis of the research presented in this thesis. In this chapter, I have explored some of the connections between this choice of meta-theory and other research approaches, and specifically focused on the implications this meta-theory has for the methods chosen to conduct the research presented in the following chapters. Specifically, I have discussed some of the issues involved in making distinctions between quantitative and qualitative research approaches, and outlined why a qualitative approach was chosen for this inquiry. I have also discussed more specifically the areas of phenomenology, narrative and participatory research, and how I see these fitting with the meta-theory guiding the research, as well as how these provide direction for the methods chosen for data collection and analysis. In the following chapters, Study 1 and Study 2 are presented.

## CHAPTER 6

TWO STUDIES TO UNDERSTAND THE EXPERIENCES OF MENTAL HEALTH

CONSUMERS BECOMING EVALUATION RESEARCHERS:

THE AIM AND RESEARCH QUESTIONS OF THIS INQUIRY

In the previous chapters, I have reviewed the literature relating to evaluation in mental health services, and the roles of consumers in mental health services research. I have also examined models of mental health and illness, and the literature relating to personal change and transition. In this chapter, I will describe the overall aims of the research conducted, articulating the specific research questions guiding the studies presented in the following chapters. A total of five research questions are posed.

### Aim

The aim of this research is to use accounts by consumers of mental health services to develop a model that presents the experiential and psychological processes of consumers in becoming researchers. Specifically, the model will apply to consumers who previously did not identify as researchers, and its development is within the mental health, and consumer-directed research context. In order to develop the model, I will first need to explore the experiences of being a consumer of mental health services, as part of the context for consumers' experience of becoming researchers. I will therefore conduct two studies, both contributing to achieving this overall aim.

My aim is to develop the model directly from the accounts of consumers: both general consumers of mental health services, in Study 1, as well as consumers involved in the transition of becoming researchers, in Study 2. Because of the range of issues relating to power differentials and the limitations of traditional approaches to working with consumers of mental health services outlined in Chapters 2 and 3, I judged that choosing qualitative approaches to conduct this research task was required. While clearly I have my own set of investments in this research, which are different to those my colleagues and co-researchers who participated hold, my aim has been to conduct this inquiry not “for” but “with” my co-researchers.

The aim, then, of Study 1 is specifically to develop a comprehensive understanding of the experiences of being a consumer of public mental health services.

The aim of Study 2 is to develop an understanding of the experiences for consumers new to research, of becoming evaluation researchers.

### Research Questions

In order to achieve my overall aim, the following research questions were used to guide the qualitative investigation that is presented in the subsequent chapters.

Research Question 1: *What are the experiences of being a consumer of public mental health services?*

To develop a comprehensive model of the experiences of becoming and being a consumer researcher, an understanding of the experiences of being a consumer of mental health services is necessary. As the aim states above, and preceding chapters have indicated, it is my intention to examine the experience of becoming a researcher specifically within the context of the mental health field, for people who have experience using services. This research question is the explicit focus of Study 1.

Research Question 2: *What are the experiences of being a consumer researcher?*

A description of the experiences of being a consumer researcher will be essential to understanding the process of becoming a researcher. Study 2 specifically explores this research question.

I have developed three further research questions to guide my exploration of these experiences, and assist in developing the model. These final three questions will be addressed by considering the data from both Study 1 and Study 2 collectively.

Research Question 3: *What is the nature of this transition, from consumer to consumer researcher?*

Research Question 4: *What emotions accompany this transition?*

Research Question 5: *What changes in self-construing occur during this transition?*

The final three research questions were developed, guided by an understanding of transition as offered by personal construct theory, focusing on three aspects of



consumers' experiences theoretically derived as pertinent to experiences of transition. These questions additionally guide the inquiry explicitly to considering the links that bridge the experiences described in Study 1 and Study 2. The data collected with Consumer Researchers, forming the content of Study 2 will directly address these questions to a large extent; however, a full elucidation will require concurrent consideration of the results from Studies 1 and 2.

## CHAPTER 7

### BEING A CONSUMER OF MENTAL HEALTH SERVICES:

#### STUDY 1 METHOD

In this chapter I will outline the method used in Study 1, for conducting focus groups and interviews with consumers of mental health services to better understand their experiences. Study 1 was conducted as part of the Consumer Evaluation of Mental health Services Project (CEO-MHS), by the Consumer Researchers and me, and so in this section, I will at times use the term “our” to refer to this team, rather than using the first person.

### Conducting Focus Groups with Consumers of Mental Health Services

The focus group method is a useful technique to assist in-depth understanding of consumers’ experiences, in their own words (Lord et al, 1987; Stewart & Shamdasani, 1998) and importantly, this method allows participants to share in the direction and focus of the discussion (Phan & Fitzgerald, 1996). Focus groups are particularly useful for exploratory research early in research projects, to establish a guide for further investigation (Stewart & Shamdasani, 1998). Morgan (1988) suggests that one of the most important ways focus groups can contribute to research studies using interview methods is in devising the interview schedules or guide. It was for this purpose, to gain an initial in-depth understanding to guide further exploration in interviews, by directly contributing to developing the interview guide, that the focus groups were conducted in this study. It was our aim to ensure that the questions we asked in interviews were relevant to consumers, and the focus groups were used to guide us in this way. As Morgan (1988) asserts, focus groups are of particular value in ensuring that research is being conducted from participants’ perspectives, “not just through a set of disciplinary filters and blinders.” (pp. 30-31). For these reasons, I believe the focus group method is particularly consistent with a mutual orientation approach to data collection, which I described in Chapter 6. Michell (1999) also argues for the inter-related use of focus groups and interviews, citing the differences she found in the type of information gathered using the two forms of data collection.

Phan and Fitzgerald (1996) and Stewart and Shamdasani (1998) identify a number of advantages that the focus group method has over other data collection methods. Some of the advantages that I believe are critical to my research include:

- Focus groups allow direct interaction between researchers and participants, which allows for opportunities to clarify, probe and follow-up ideas. Participants are able to be actively involved in developing and qualifying their responses.
- Focus groups are socially oriented, which places people in more natural, real-life situations as opposed to controlled experimental conditions.
- The social nature of the data collection may produce data or ideas that might not be uncovered in more individual data collection contexts.

Consumer Researchers, working as part of the CEO-MHS team, facilitated the focus groups, which were transcribed verbatim. Kitzinger and Barbour (1999) have discussed the importance of group facilitators prior knowledge, their “ability to be able to pick up on or interpret the language, terminology, gesture and culture meanings” (p. 13) of those people with whom they are working. It was agreed by the CEO-MHS Management team (academics and consumer representatives) that Consumer Researchers should conduct the focus groups and interviews with other consumers. Earlier, I have also outlined the strong case for consumers’ involvement in all stages of the research process. The facilitators’ roles were to guide participants through focused discussions, posing the questions that had been devised and keeping the discussions on topic. They were supported by the two Consumer Representatives from the Management Committee, who acted as co-facilitators with them. The co-facilitators were present to support the facilitators specifically by managing the equipment during the focus group – making sure the tape was working, changing the tape, if needed, when a side was full. However, co-facilitators were also available for any other supporting role the facilitator requested during and after the focus group. I also provided support pre and post focus group discussions.

## *Participants*

A total of 20 people participated in the focus groups: 10 men and 10 women. Participants were recruited from the Illawarra/Shoalhaven area of NSW, Australia. Participants ranged in age from 27 to 60 years, with a median age of 41.5 years. These participants had contact with a public mental health service for a median of 6.5 times in the month prior to the focus group. The range was 0 to 26 times. The last time they had had contact ranged from the day of the focus group to four years prior. When presented with demographic surveys to complete, participants were encouraged to fill the survey in as completely as possible, however, were also reassured that they need not answer any question they preferred not to. Participants did, therefore, select which questions to which they responded. Table 2 shows the employment status of participants. Ten percent of participants chose not to respond to this question. Table 3 includes the income range, with 25% of participants choosing not to respond.

Table 2

*Employment Status of Focus Group Participants (n=18)*

Employment Status	Percentage
Full-time	11%
Part-time	17%
Casual	6%
Unemployed	44%
Not in work force/retired	22%

Sixty percent of participants had been admitted to a psychiatric ward sometime in the past. Table 4 shows the percentage of participants who had voluntary and/or involuntary admission experiences. Of these participants, the median number of admissions was 4.5,

with a range from one to 40 admissions. One participant reported having lost count of the admissions they had had. Twenty-five percent of participants had never been admitted to a psychiatric ward, while 15% of participants chose not to respond to this question.

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Table 3

*Income Range of Focus Group Participants (n=15)*

Income Range	Percentage
\$0-9,999	53%
\$10,000 – 19,999	33%
\$20,000 – 29,999	7%
\$30,000 – 39,999	0%
\$40,000+	7%

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Table 4

*Type of Admissions to Psychiatric Ward of Focus Group Participants (n=11)*

Status	Percentage
Voluntary patient	45%
Involuntary patient	27.5%
Experienced both	27.5%

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Participants reported a range of diagnoses. These are provided in Table 5. Thirty percent of participants, however, chose not to respond to this question.

The study had received approval from the human research ethics committee of the affiliated university, and each participant gave informed consent to take part in the focus group discussions (See Appendix A for examples of forms).

Table 5

*Reported Diagnoses of Focus Group Participants (n=14)*

Diagnosis	Percentage
Schizophrenia	36%
Depression & acute anxiety/stress	22%
Major depression	14%
Bipolar disorder	14%
Psychosis due to organic brain disorder	7%
Have not been informed	7%

*The Focus Group Guide*

The following questions were used to guide the discussions:

- What have been your experiences of mental health services – the good and the bad?
- What needs do you think a mental health service should meet?
- How do you think the mental health services, and the service you receive (or have received), could improve?
- I'm wondering what questions you would like to be asked about the mental health service?

At this stage, participants were shown a summary of the National Standards for Mental Health Services (Australian Health Ministers, 1997) and asked:

- These are some areas people have found important to them. What do you think?

These questions were determined through a series of meetings involving the facilitators of the focus groups, as well as Management Committee meetings. The format of the focus groups was semi-structured, which meant that while facilitators had to ensure

the areas covered in these questions were dealt with in the discussion, the group participants were also free to help set the tone for the discussions.

### *Analysis of Focus Group Responses*

The focus groups were analysed qualitatively, using the Interpretative Phenomenological Analysis method (IPA) (Smith, 1996; Smith, Flowers & Osborn, 1997; Smith, Jarman & Osborn, 1999; Smith & Osborn, 2003). The aim of the focus group discussions was to understand the consumers' perspectives, particularly in relation to evaluating public mental health services. With this type of aim, a qualitative approach to analysis is most useful (Maykut & Morehouse, 1994; Lyons, 1999).

IPA was chosen as the method of analysis because of its focus on personal meanings, while centrally recognising the interpretative process of analysis (Smith et al, 1999). IPA is concerned with the way people think, in relation particularly to the issue being researched (Flowers, Smith, Sheeran & Beail, 1998). Unlike discursive analysis methods, IPA, while recognising that thoughts are not transparently available via transcripts, involves interpretation of the data with an aim to say something about the way participants think (Smith et al, 1999). In contrast, discourse analysis is concerned with language itself, regarding verbal reports as behaviours in their own right (Smith et al, 1999). Discourse analysis then, focuses more on why people talk about things in the particular way demonstrated, whereas IPA focuses on the meanings people give to the things they talk about (Flowers et al, 1998).

While IPA is a relatively new method of analysis, still described as exploratory and under development, (Smith et al, 1999), a comprehensive sequential process for conducting IPA is adopted, outlined by both Smith et al (1999) and more recently, by Willig (2001). However, the authors highlight that IPA, and indeed qualitative methods generally, involve adaptation. Specifically, IPA, in placing interpretation central to the method requires adaptation of the process of analysis, as the researcher/analyst becomes



personally involved (Smith et al, 1999). The sequential process, therefore, is offered by Smith et al (1999) as a suggestion, rather than a fixed protocol. The analysis process involves four steps: (1) close reading and note making of each transcript; (2) analysis of individual transcripts and broad labelling of themes, resulting in development of a list of themes for each transcript; (3) comparison of the lists across transcripts, with themes re-clustered and collapsed, resulting in a master list of themes; and (4) use of the master list to code all data across the transcripts.

IPA has been used as an analysis method in a number of studies within the mental health field in recent years. These studies have explored consumers' experiences and perspectives of first episode psychosis (O'Toole et al, 2004), delusions (Rhodes & Jakes, 2004; Rhodes & Jakes, 2000), stigma (Knight et al, 2003), anorexia (Colton & Pistrang, 2004; Jarman, Smith & Walsh, 1997) and self-harm (Alexander & Clare, 2004; Crouch, Wright & Crouch, 2004). IPA has also been used to understand peoples' experiences of the onset of Alzheimer's disease (Claire, 2002; Pearce, Claire & Pistrang, 2002), the experience of being a stroke survivor (Murray & Harrison, 2004), the role of social support for women with chronic pain (Warwick, Joseph, Cordle & Ashworth, 2004), living with brain injury (Howes, Benton & Edwards, 2005) and also to understand people's experiences of hospital counselling on orthopaedic wards (Schoenberg & Shiloh, 2002). IPA has also been adopted as methodology for understanding life transitions, such as first time parent-hood (Bradley, Mackenzie & Boath, 2004; Smith, 1994 & 1997).

In Chapter 6, I described a number of approaches that authors have outlined as contributing to good qualitative research. Central to many of these discussions is the importance of that ensuring multiple readings of the data occur, and that others, including the participants of the study, are involved in developing and checking the interpretations made. For example, Fossey et al (2002) talk specifically about issues of interpretative rigour, and Manning (1997) discusses fairness as a dimension of authenticity in qualitative research. Verification of the focus group themes occurred at two levels. The

first level addressed whether the interpretation made captured the meanings conveyed by participants, and thus was at an interpretative level. Once I had completed this primary analysis, one external consumer consultant, and two consumer researchers were provided with complete transcripts of the focus groups, labels and explanations of the themes from my analysis, as well as a series of questions to answer. These questions were as follows:

1. How does this analysis fit with your understanding of the discussions represented in the transcripts?
2. How adequately does this analysis capture overall the meanings expressed in the focus group discussions?
3. What has been missed in this analysis?
4. What has been included that you would delete from the analysis?
5. Do the labels used fit the data? Do they capture the themes adequately?
6. Would you use different labels to discuss these themes? If yes, what would your labels be?
7. What other comments do you have – about the data or the analysis?

Changes were then made to the analysis, based on the feedback provided by the external consumer consultant, and the two CRs. These changes were:

1. The theme of Power (which later became Power and Disempowerment) was included in the interpretation, as a latent theme;
2. The concept of fear (of not getting help etc) was incorporated into the analysis, also within the theme of Power/Disempowerment;
3. The concept of responsibility too, was incorporated into discussion of the theme Power/Disempowerment;
4. A further sub-category, Diagnosis, was added to the manifest theme Quality and Completeness of Care;
5. Several labels were changed to better reflect a consensual interpretation: Isolation became Isolation and Loneliness; Power was changed to Power and

Disempowerment. The sub-theme 1.2 Mental health issues not taken seriously, was altered to read Mental health illness/issues not taken seriously. The manifest theme Completeness and Quality of Care was reorganised to read Quality and Completeness of Care. The theme Information was relabeled Information and Education, and its sub-theme 5.3 Staff knowledge/education, was relabeled Mental Health Service staff and auxiliary services staff knowledge/education.

At a later point, the latent themes of Isolation and Loneliness, and Community were collapsed into a single theme, as the bipolarity of these themes was explored further, and an interpretation of these as complementary alternatives was agreed upon.

As is often the case, my interpretative process continued through writing this chapter (Denzin, 1994; Miller & Crabtree, 1999), and while the essence of the themes remained, I further developed the labels during this writing stage, as I wanted to draw the two sides of each construct out more fully. As I started writing, only about half of the theme labels reflected the contrasting alternatives inherent in each of the issues that form the themes.

Eight themes were identified from analysis of the focus groups, and agreed on by the team. Six of these themes related directly to how the participants perceived themselves in relation to mental health services, and were labeled: Valuing versus Devaluing of the person; High versus low quality and completeness of care; With/without Resources; Involvement versus Lack of Involvement; Availability versus Inadequacy of Information and Education; and Positive and Negative Medication Experiences. These six themes were discussed by participants in the context of the experience of living with a diagnosis of mental illness, and two latent themes were identified to reflect this, and are inter-connected. These we labeled Isolation and Community, and Power and Disempowerment. These two themes connect the other six, and stem from the conversations all the participants had.

The second level of verification involved coding specific segments of the transcripts by several people, to ensure the themes we had agreed on were being consistently applied to the transcripts. I carried out this level of verification with my colleagues from the team who had also worked on the first level of validation. The members of this team each coded sections of text, using the themes from the analysis. The application of themes could then be compared across three coders.

A two-thirds percentage agreement between coders was used to directly address the issue of power between consumer and non-consumer members within the team, to ensure that power in interpretation of the text did not lie solely with me: a non-consumer PhD student. Using a 2/3 agreement method, with two consumer and one non-consumer coders, this meant that when any two of the three researchers agreed on a code for specific text, this interpretation of the text was adopted as the interpretation for the project team.

Strong agreement between at least two of the three coders was found for both the manifest and latent themes in each focus group. Coding of the manifest themes was consistent, with agreement across focus group transcripts between 88% and 95%, and 100% agreement was found across the focus groups for coding of the latent themes. These percentage agreements, with a two-third criterion, are shown in Table 6.

Table 6

*Two Thirds Percentage Agreements for Manifest and Latent Themes for Study 1 Focus Groups*

	Focus Group					
	1	2	3	4	5	Average Total
Manifest Themes	88%	93%	93%	94%	95%	93%
Latent Themes	100%	100%	100%	100%	100%	100%

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## Conducting Interviews with Consumers of Mental Health Services

Interviews in qualitative studies are typically conducted in unstructured or semi-structured formats (Mertens & McLaughlin, 1995), although interview methods also encompass the possibility of more formally structured approaches as well. Smith (1995) indicates: “researchers use semi-structured interviews in order to gain a detailed picture of a respondent’s beliefs about, or perceptions or accounts of, a particular topic.” (p. 9). Similar to the advantages of conducting focus groups, advantages of adopting semi-structured interviewing for data collection include: greater flexibility for the researcher and participant than more structured forms of data collection; and personal interaction between the researcher and participant, which allows for more creative, spontaneous and personal information to be discussed (Smith, 1995).

In conducting semi-structured interviews, the researcher has a set of questions (an interview guide or schedule) to assist them, however, the interview is guided, not determined, by this set of questions. A feature of semi-structured interviewing is that the interviewer is free to probe interesting areas that arise in discussion, and that the respondent is also free to raise their interests or concerns, and affect the course of the interview. Smith (1995) summarises the advantages of the semi-structured interview as including: it facilitates rapport and empathy; allows flexibility of coverage and enables the interview to enter novel areas; it produces rich data. These advantages are supported by Kvale’s (1996) discussion of semi-structured interviewing.

Consumer Researchers, working as part of the CEO-MHS team, conducted 33 interviews with consumers of mental health services. The interviews were transcribed. CRs role were to guide participants through the semi-structured interview, posing the questions we had devised and keeping the discussion on topic. An explicit aspect of the interviews was for CRs to convey a sense of empathy, allowing the participants to feel their voice was being heard. CRs had attended several training sessions in conducting

interviews as part of their employment on the CEO-MHS project (McLeod & Oades, 2001). Support was available in a variety of forms for CRs throughout their employment, and was particularly emphasised during the interviewing stage of work. Support was explicitly viewed as the responsibility of the entire research team: I facilitated regular team meetings during the period of interviewing; CRs had access to phone numbers for both CR and academic team members; an opportunity for debriefing immediately after interviews was offered by another team member, usually myself, the Project Officer from the team, or one of the two Consumer Representatives from the Management Committee. CRs were also encouraged to work in a buddy-system with a designated partner from the team in offering mutual support. Additionally, I provided supervision, which involved joint reflection with CRs on their skills as interviewers. This approach to supervision and support was guided by the concept of dispersed dependency and its importance during change, within personal construct theory (Kelly, 1955/199; 1969; Walker, 2003).

#### *Using the Focus Group Themes to Develop the Interview Guide*

The questions posed in our interviews were developed, based on themes that had emerged from focus group discussions our team held with mental health consumers previously. Two groups of CRs from the team worked independently to draft a proposal for the interview questions, using the themes from the focus groups. A series of meetings discussing the two proposals were then held, with CR and academic members of the team, to refine and structure the final interview questions. The resulting interview guide consisted of eight questions each followed by a series of prompts: the first two questions were broad open-ended questions inviting participants to discuss their views of mental health services generally and the other six questions revolved around issues identified in analysis of the focus groups. The interview guide is provided in Appendix B.

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*Participants*

A total of 33 mental health consumers participated in interviews, 14 men and 19 women. The study had received approval from the human research ethics committee of the affiliated university, and each participant gave informed consent to take part in their interview.

*Sampling.*

We adopted a purposive sampling method of maximum variation sampling for recruiting interview participants. Purposive sampling is a method where information richness is sought, by seeking specific types of data sources based on an a priori, flexible determination of the boundaries of the investigation (Kuzel, 1999). Purposively selecting participants recognises a goal of attempting to understand, consistent with our aim, theoretical framework, and analysis method, compared to the goal of generalisation that is more common to quantitative research (Kuzel, 1999; Maykut & Morehouse, 1994). Purposive sampling is adopted within qualitative studies because the number of participants involved is almost always much smaller than within quantitative research, and leaving participant choice to randomness may result in data that does not aid further understanding of the topic of interest (Kuzel, 1999). The maximum variation method involves looking for diverse variations to see what patterns are consistent (Miles & Huberman, 1994; Patton, 1990) in responses. Specifically, we sampled for consumers who had a range of experiences with: different types of service settings; with frequency and recency of contact with services; geographical setting of services used; cultural and linguistic backgrounds; mental health literacy, which we defined in terms of their advocacy experiences, and knowledge of broader policy; and choice in treatment, in terms of their perception of themselves as involuntary or voluntary users of mental health services. In addition to these sampling areas, we sought to balance gender and ensure a

range of ages. We purposively sought participants in four age brackets: under 30, 30 -44; 45-59, and over 60.

These sampling areas were determined through a series of team meetings considering the question *what are the important variables that may affect consumers' experiences of public mental health services?* and four sampling parameters: settings; actions; events; and processes (Miles & Huberman, 1994). Consumer Researchers, and Management Committee members used their knowledge of mental health services to consider this question. Additionally, we incorporated feedback from 1. earlier conference presentations; and 2. two external consumer consultants (Maykut & Morehouse, 1994) into producing our sampling approach.

#### *Descriptive information.*

Participants' ages ranged from 20 to 68 years, with the median age being 44 years. Table 7 indicates the percentage of participants within each of the four age groups our sampling was based on.

Participants reported they had contact with a public mental health service between 1 and 30 times in the two months prior to the interview. The median was 4 for those participants still in contact with mental health services (n=29). The last time they had had contact ranged from the day of the interview to nine years earlier. Participants reported a range of between three and 44 years since first having contact with a mental health service. All interview participants reported having been hospitalised, with four participants indicating this had occurred only once. The length of stay in hospital participants reported ranged from one night, to a maximum of 2 years.

Participants reported having used a broad range of mental health service types and settings including inpatient and outpatient services, community services, rehabilitation services, drug and alcohol services, as well as emergency and crisis teams. In terms of the geographical status of services used, interviews were conducted with participants from



Table 7

*Age Distribution of Study 1 Interview Participants (N=33)*

Age Bracket	Percentage
< 30	18.2%
30 – 44	30.3%
45-59	39.4%
> 60	12.1%

Wollongong and Shoalhaven, Sydney, Orange, Parkes and Condobolin. See the map of New South Wales, Australia, in Appendix C. These areas were selected for purposive sampling based on scores on the Accessibility/Remoteness Index of Australia (ARIA, Commonwealth Department of Health & Aged Care, 2001<sup>b</sup>). The ARIA scale is used to geographically interpret remoteness, through accessibility (road distance) to 201 specific service centers. Remoteness is identified with lack of accessibility to services regarded as normal in metropolitan areas. ARIA scores range from 0 – 12, and the scale defines five categories, which are: Highly Accessible (ARIA score 0 – 1.84); Accessible (ARIA score >1.84 – 3.51); Moderately Accessible (ARIA score > 3.51 – 5.80); Remote (ARIA score > 5.80 – 9.08); and very Remote (ARIA score > 9.08 – 12). Based on postcodes:

- Wollongong has an ARIA score of 0.19, falling within the Highly Accessible category;
- Shoalhaven (based on a Nowra postcode) has an ARIA score of 1.4743, falling within the Highly Accessible category;
- Sydney has an ARIA score of 0, falling within the Highly Accessible category;
- Orange has an ARIA score of 2.0854, falling within the Accessible category;
- Parkes has an ARIA score 3.0008, also falling within the Accessible category; and
- Condobolin has an ARIA score of 7.1692, falling within the Remote category.

Within the state of NSW, only four postcode areas fall into the very remote category of the ARIA.

While Table 8 shows that most participants were born in Australia, 7 interview participants were born overseas. Six interviews were conducted with the use of an interpreter, as English was not the preferred language for these participants. In total, nine participants reported that they spoke a language other than English at home. These languages included Arabic, Chinese, Spanish, French, Hungarian, Macedonian, Serbian, Vietnamese and Turkish. In addition, participants reported a broad range of ancestry, and although no participants identified as Aboriginal or Torres Straight Islander, one participant indicated having Aboriginal ancestry.

Table 8

*Study 1 Interview Participants Country of Origin (N=33)*

Country of birth	No. of participants
Australia	26
Yugoslavia	2
Norway	1
Macedonia	2
Vietnam	1
Turkey	1

Of the 33 participants interviewed, eight people worked in the Mental Health area, some of these for peak consumer organisations. Twenty participants rated themselves as highly experienced using public mental health services, and nine stated that saw themselves as highly experienced in Consumer Representative roles. Twenty-one of the 33 participants

rated themselves as highly confident in making recommendations about mental health services.

One participant chose not to respond to the question asking about hospitalisation experience. In total, 15 participants reported being voluntary patients when hospitalised, eight reported experiencing involuntary hospitalisation, while a further eight participants reported experiencing both at various times.

While participants' diagnosis was not a sampling category, participants reported a range of diagnoses. These are outlined in Table 9. Two participants did not respond to this question. Similarly, employment status and income range were not linked to our sampling strategy, however these data are summarised in Table 10, and Table 11 respectively.

Table 9

*Reported Diagnoses of Study 1 Interview Participants (n=31)*

Diagnosis	Percentage
Schizophrenia	42%
Major depression	6.5%
Bipolar disorder	25.8%
Acute anxiety disorder, endogenous depression	3.2%
Bipolar, brain injury, personality disorder	3.2%
Depression/bipolar	3.2%
Chronic anxiety, depression, OCD	3.2%
Depression, schizophrenia, OCD, anxiety	3.2%
OCD and depression	3.2%
Have not been informed	3.2%

Table 10

*Employment Status of Study 1 Interview Participants (n=31)*

Employment Status	Percentage
Full-time	9.7%
Part-time	29%
Casual	0%
Unemployed	32.3%
Not in work force/retired	29%

Table 11

*Income Range of Study 1 Interview Participants (n=24)*

Income Range	Percentage
\$0 – 9,999	54.2%
\$10,000 – 19,999	33.3%
\$20,000 – 29,999	4.2%
\$30,000 – 39,999	0%
\$40,000+	8.3%

*Analysis of Interview Responses*

Analysis of interviews was conducted by myself and one Consumer Researcher from the team. In addition, a further CR was involved in preliminary analysis for the purposes of guiding sampling decisions during the interviewing, as described below. Consistent with a philosophy of involving consumers in research, in a progressive and incremental manner across the span of the research project, the role consumer researchers

played in interpretation of interview data built on their role in interpretation of focus group data. CR involvement increased to open, independent interpretation of interview data at this stage of the research. For this to occur, it was necessary for the CR involved to be trained in: 1. the use of the computer programme NVivo (QSR International, 2002), which both interpreters used to manage data analysis; and 2. the method of analysis IPA.

*Integration of analysis with purposive sampling phases.*

Interviewing occurred in two phases, given the purposive method adopted for sampling. Sampling decisions, as described earlier, were initially based on knowledge from literature and experience, however subsequently, sampling decisions were based on analysis of interview data. This method is typically adopted in qualitative research (Patton, 1990), however usually a single researcher conducts interviews and a concurrent analysis, making decisions about sampling needs continually, and reflectively. Conducting interviews in several phases makes this method achievable with a large team conducting interviews. Additionally, given the collaborative nature of the project, it was necessary to have at least two people, one a CR, involved in analysis of interview transcripts.

Final analysis was conducted with all interview transcripts once the second phase of interviewing had been completed. However, an initial analysis for reflection on sampling decisions occurred at the completion of Phase 1 interviews. This was used to guide sampling for Phase 2. The initial analysis at the completion of Phase 1 interviewing was conducted with explicit consideration of sampling decisions. IPA, as described earlier in this chapter, was adopted by the author and two CRs from the team, and initial lists of themes were developed, although these lists were not intended to be exhaustive, at this stage. These were then compared, and this team collectively discussed their impressions of the data gathered to date. A broad range of themes were then seen, as represented in the transcripts, and it was agreed by these interpreters that saturation was

close to reached. There were, however, several themes emerging that we agreed further information could be gained about, through further interviews. Reflecting on the original sampling categories determined for the sampling strategy, it was agreed that more effort was required to target participants in the under 30-age range, and participants from a greater variety of cultural and linguistic backgrounds. The second phase of interviewing was conducted on this basis.

One of the CRs above, and I, conducted analyses of the interview data. The initial sampling analysis became the basis from which the final analyses commenced. This Consumer Researcher analysed 75% of the interview transcripts, while I conducted an analysis using all interview transcripts. The two separate analyses were conducted using an adaptation of the IPA method outlined earlier, for larger numbers of transcripts (Smith et al, 1999). A final interpretation was agreed on between the two interpreters. Agreement was reached over a series of meetings where the interpreters identified and agreed on congruent or overlapping interpretations, and established labels for these. Differences in analyses were discussed, reflected upon, and agreement was then reached as to whether to include these themes, or if they were incorporated in interpretations already in the common analysis.

Ten themes were agreed on by the interpreters. During the writing of this thesis, similar to the focus group themes, further refinement of the labels for these ten themes occurred. It is often the case with qualitative research in the interpretative paradigm that interpretation continues as part of writing and communicating themes (Denzin, 1994; Miller & Crabtree, 1999). The themes found were: Acceptance versus stigma; Highly informed and educated environment versus poorly informed and educated environment; Power and powerlessness; Consumer involvement versus lack of consumer involvement; Optimal and appropriate versus inadequate and inappropriate medication experiences; High versus Low Service Quality System; Responsive or Unresponsive to consumers; Satisfying versus dissatisfying relationships with staff; Supportive versus unsupportive of

relationships with their community, family and other consumers; and All of me versus “me” as an illness (Malins, Oades, Viney & Aspden, 2005). Some of these themes incorporate a number of sub-themes.

Verification of this analysis, agreed on by the interpreters, occurred by seeking feedback from the interview participants. Feedback occurred in formal feedback sessions, where participants were invited to attend and hear about the analysis and provide their feedback. These feedback sessions were an important component of conducting participatory, empowering research with consumers of mental health services (Fossey, Epstein, Findlay, Plant & Harvey, 2002), and is an important element of engaging in a Mutual Orientation approach to research (Viney, 1987). Sharing analyses and seeking dialogue about these analyses with research participants is essential to achieving authenticity (Manning, 1997, Fossey et al, 2002). Four feedback sessions were conducted across NSW to ensure all participants from interviews could attend a session held at a venue easily accessible to them. Participants from focus groups were also informed of their local feedback session, and invited to participate.

We clearly stated that the purpose of these feedback sessions was to check “did we get it right?” from their perspective. Participants from interviews who agreed to attend the feedback sessions were provided with a written summary of the analysis prior attending the session. The session itself was structured with a presentation, by a range of team members, outlining and discussing the CEO-MHS research broadly, then discussing the interview themes specifically. This presentation normally took about an hour, during and after which participants were encouraged to ask questions. Participants were then invited to remain, and take part in a focus group, facilitated by CRs who were not involved in analysis of the interview transcripts, but who had a clear understanding of the crucial themes. No academic/non-consumer members of the team remained for the focus group, consistent with the overall project philosophy that consumers be interviewed by CRs.

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Strong support for the analysis as presented was found in these feedback sessions. Participants were asked if the labels used for themes were adequate, and while one participant suggested that the theme “all of me” be relabeled “ME”, other participants in feedback sessions indicated their strong approval for the label as used in analysis. Comments about the analysis included reference to the wholistic nature of the themes as a positive feature of the analysis; the commonality of experience, no matter what diagnosis a consumer received; the themes described resonate with participants’ personal experience, and experience of other’s known to participants. Some participants said that they agreed with the themes, based on their “lived experience”.

### Conclusions

In this chapter, I have described the method used in conducting Study 1. Study 1 consisted of two complementary parts: focus groups conducted with twenty consumers of mental health services, followed by interviews, conducted with thirty three consumers. The interview guide was determined using themes from the focus group stage to direct the questions asked. The results of Study 1 are presented in the following chapter.



## CHAPTER 8

EXPERIENCES OF BEING A CONSUMER OF MENTAL HEALTH SERVICES.

STUDY 1: RESULTS

In this chapter I will present the results from Study 1. I will begin by discussing the themes that resulted from analysis of data from Focus Groups. These themes, as described in the previous chapter, were used to help frame the team's approach in conducting interviews. Themes derived from analysis of data collected in interviews will follow the focus group themes, developing a fuller picture of the experiences of being a consumer of mental health services.

### Being a Consumer of Mental Health Services: Results from Focus Groups

Eight themes were identified from analysis of the focus groups, and agreed on by the team. Six of these themes related directly to how the participants perceived themselves in relation to mental health services. These six themes were discussed by participants in the context of the experience of living with a diagnosis of mental illness, and the interpreters identified two latent themes that reflect this, and are inter-connected. These two themes connect the other six, and the conversations in which the participants were engaged. The themes are presented in Table 12.

Each theme will now be discussed in detail, beginning with the latent themes Community and Isolation, and Power and Disempowerment, which create the context for the six remaining themes that follow. Pseudonyms have been used in this description of the focus group themes to assist the clarity of focus group excerpts when more than one participant is quoted.

#### *Community and Isolation*

Isolation and loneliness weave in and out of the discussions, both explicitly and implicitly. Some participants directly label their experiences of loneliness and isolation. For example, one participant states:

They used to have [specific rehabilitation service, now closed]...that used to give me sort of a purpose to get out of bed and to, and not to be lonely, but they actually sold [service] ...it was sort of like a club house setting...

Direct expressions of loneliness or isolation are typically embedded within discussions around issues relating to the health service and provision of care or resources. This is not surprising as this was the purpose of the focus group discussions. The questions posed, while open questions, were directed towards insights into consumers' perceptions of the mental health service. While the participant above did not elaborate further, the confining isolation of living with a diagnosis of mental illness is strongly conveyed by the link she makes to a sense of direction and purpose in her life.

The experience of isolation and loneliness is touched on many times throughout the focus group discussions in many forms of sharing. Often, expressions of loneliness and isolation are woven into discussions of after-hours care. For example:

One thing is the fact that I think the crisis team, the service stops around 8.30...most people with a mental illness, the worst time is during the night for anxiety and depression...during the day we've got company...but during the night we're at home by ourselves.

Some participants refer to the intangible nature of their illness, again conveying a sense of isolation. One participant, when discussing attempts to get help within the hospital system says:

...you can go in there on emotional life support, and providing you look all right through the window, they don't care. Broken arms and broken legs are more important than broken heads. [They] can't see your pain, so they don't appreciate it or prioritise you accordingly.

Echoed by another participant later in the same discussion:

I think they have an attitude problem with compassion and understanding. Sometimes it's with anything, because you can't see the mind and what someone's thinking, it's very hard to know exactly what the problem is...sometimes when you're actually talking to them, they don't get the real zest of the problem, because you can't see it.

Living with a mental illness, despite mental health services, often means for these participants a lone struggle, as the intangible nature of the illness places a barrier between themselves and others – mental health professionals in these examples. Few people are able, or willing, to understand their experiences. These discussions of the intangibility of the illness express a devastating sense of loneliness.

Inextricably bound to the experiences of isolation is the theme of community. Community is strongly woven into the discussions: a strong desire for community, camaraderie and sense of consumer community, as well as alienation from the community. Most explicit references to isolation or loneliness by participants are made within the context of discussing their social needs. For example, one participant reports her own experiences of isolation, while at the same time expressing concern for others going through similar experiences:

A lot of us...I'm not at the moment, but I used to be, I'm a lot better than I was, but I used to be isolated. And that socialisation is a first step of walking again. You know how you say you've got to crawl before you walk. That socialisation...but they've got government facilities now, but they're treating it more like a workplace. But I still believe even though it sounds irrelevant, that the social side of it is very important. Because the ones that are really isolated and really down in the dregs like I used to be, need...need support first, and the social side of it first, before they can get any further. It's the first start of getting better. And they're sort of not looking at that as very important any more, but it is. It's very important.

This participant examines her own experiences of being isolated within the context of her social support needs, placing social support at the very centre of her rebuilding and recovery. Here it seems there is a contrast between isolation/loneliness versus being supported and having a social network. The awareness and extrapolation of their own experiences, to those of other consumers, is typical of the discussions in the focus groups.

The theme of community runs through many of the six themes relating to service provision, most particularly the themes valuing/devaluing of the person; High versus low quality and completeness of care; and Involvement versus lack of involvement. A sense of alienation from the community is conveyed by participants throughout the discussions. Some participants convey this sense in terms of the withdrawing impact of mental illness. For example one participant, when discussing resource needs, specifically talking about needing a place for consumers to congregate and meet, comments: “it’s a stepping stone back into society”. The use of the word *back* conveys distance from community, alienation, and a desire to rejoin, to belong. At an explicit level the participant is talking about what services are provided for out-patients, however implicitly *back* infers a comparison and loss – an attempt to return to something that was.

Alienation at a more profound level is conveyed by another participant through his use of the distinction of “normal” people: “When you’re ill, sometimes you don’t relate to normal people, and they don’t want to go near you because you’re ill...it means you get lonely, see? It gets very isolating.” Later in the discussion, this participant elaborates further on his relationship with ‘normal’ people:

Because normal people don’t want to know you, and I understand that.  
Because you know, they’re just going on with normal life, they’re capable.  
But we’re just, well, I’ll speak for myself, I can’t handle a lot of stress, I can’t do a lot of things. So therefore, you’re different...you know ... I’m happy that they’re well [laughs]. I want to be like that too, but it’s just the fact that you’re not. You’ve got to accept that.

The divide for this participant, between himself and the “normal” world is enormous. However, entwined with this chasm is a sense of camaraderie, or of consumer-community. The un-stated dichotomy seems to be that of “normal” people and consumers: there is the construction of an insular community.

While other participants do not make this distinction so explicitly, a strong sense of, or desire for, consumer community is conveyed throughout the discussions. Again, this is often conveyed through discussion of service or resource provision. For example, the above participant conveys a desire for consumer community in terms of accommodation resolutions: “we’re all in the same boat, so why not live together and make life – ah – we wouldn’t be lonely”. Shared experience and empathy underlines this sense of consumer community, and the sense of community spirit is tremendous – at times becoming a sense of responsibility. The following excerpt from one focus group discussion illuminates this sense of community spirit, with a culmination in expressed responsibility:

I think it would be a good idea to sort of have a club house setting, you know, where people can come and go, and chat to each other...

[note- this participant goes on to reminisce about a specific rehabilitation service she used to visit that has been closed down]

Robyn: do you miss that do you?

Helen: yeah, I get very, very lonely. I’m sure um, yeah, a lot of people do –

Robyn: mmm. Yeah, that was one thing that I felt, because I was quite interested to get involved, in like, in consumer advocacy, or something like that. And one thing that Helen said, that we can help as consumers...[we could] visit people who come out, and have that contact. I’ve actually had a few people from the hospital phone me up, that I have gone and visited them. And the main thing that they have said is that they do feel terribly lonely...now if that loneliness is fuelling their problem, we have a duty of care to help alleviate that, like to cut down on that. I think as a community we should take responsibility to reach out to people and help each other. And maybe we can get rid of that stigma that other people have towards mental

health, if we still are helping each other as a group, and sort of bringing in family members...

Alienation from community is further conveyed in other groups via discussions about stigma, which is alluded to above. For example, in one focus group the following discussion was held:

Richard: yeah, they just, as I said on the way over here, there's a general consensus of opinion in the community, widespread, is get on with it, and get over it. And sometimes it just doesn't work.

Karen: stop feeling sorry for yourself. It doesn't work that way, it's an illness, people have got to realise it's an illness.

Richard: yeah. And there's a certain amount of stigma associated with being mentally ill.

Karen: some people think it's all in our mind. It's not there, it's how we think. We've got the attitude problem. It's an illness.

### *Power and Disempowerment*

This theme, Power and Disempowerment, like Community and Isolation, a latent theme, runs through the focus group discussions, becoming another thread between the other six themes. The theme of Power and Disempowerment is most frequently apparent through participants' discussion about the power of others, particularly mental health professionals, and accompanying this, a sense of personal disempowerment. Participants relate experiences when they felt uninformed: "I wasn't told what was wrong with me...it was only through my GP that I found out what was wrong with me."; and disrespected: "they need to treat you like any other member of the public." The sense of power imbalance is strongly conveyed in these discussions, and this raises the question of responsibility.

The theme of power is evident in each of the six manifest themes. The statement “you don’t have a voice with them” captures the sense of disempowerment, and the alternate powerful position of mental health professionals conveyed by participants in the focus groups. Specifically, power is tightly linked to the themes Valuing versus Devaluing of the person, Availability versus Inadequacy of Information and Education, and the theme Positive and Negative Medication Experiences, particularly the sub-theme of over/mis-medication. For example, one participant says:

...they were drugging me so harshly, I was actually physically falling over and banging my head...and I was so concerned that I was falling over, I would ask them and plead with them, but they just seemed to be drugging me more and more. And the more they drugged me, the more I fought...

While explicitly, this participant is recounting an experience of being over or mis-medicated, a strong undercurrent to this story is the imbalance of power: her experience of feeling disempowered. Power imbalance is inherent in many of the six manifest themes. Captured in the theme of power and disempowerment, is the insecurity and fear accompanying the experience of disempowerment. While not explicitly stated by participants, when power imbalances are expressed, and experiences of disempowerment related, there is an underlying expression of fear and insecurity. In the above example, the experience of losing physical stability, “falling over” because of being so strongly medicated, not only is disempowerment conveyed, but an inherent insecurity in being so disempowered and in physically losing control. The use of the word “plead” profoundly states both the disempowerment and the fear, carrying connotations of desperation, fear and being totally disempowered. This sense of fear and insecurity is part of the experience of disempowerment.

The language used by participants throughout the focus group discussions conveys the struggle of power imbalance. A “them” and “us” style of language is adopted by many participants, and as I noted above discussing the theme Isolation and Community, one



participant distinguished between himself and “normal” people. This way of talking conveys the issue of power: the powerful “them” and disempowered “us”. Another participant approaches identifying her opinions with an apologetic tone, saying: “But I still believe, even though it sounds irrelevant, that the social side of things is important.” The way the participant says this, and the conveyed idea that to others, what she sees as highly valuable will be irrelevant, are strong expressions of a sense of disempowerment.

The theme of power, which like community is rarely apparent, is conveyed by one participant’s account of a doctor who was supportive of the participant, encouraging her use a creative outlet rather than hospitalisation. The participant says: “And if it wasn’t for that approval – of authority to say it’s all right to do that – I probably wouldn’t do it.” This is a profound expression of the participant’s experience of a sense of disempowerment. Despite successfully managing in a different way, using her creativity rather than hospitalisation, this participant expresses her need to have an authority’ figure’s “approval”.

Power and powerlessness are communicated in another participant’s discussion of waiting until the last moment to seek help:

The unfortunate thing is, you wait until you hit rock bottom, because you know the situation, there’s not a lot of time for you, you wait until you hit rock bottom before you try to find help again, and there’s no-one around.

This participant clearly believes that the system will let her down, conveying a sense of hopelessness, of giving up: an acute sense of disempowerment.

### *Valuing versus Devaluing of the Person*

This theme, the first manifest theme, was represented strongly in every focus group. Based around the dichotomy of valuing versus devaluing the person, the theme incorporates the notions of respect and dignity or lack of them, and how the mental health service conveys these messages. Included within this were the sub-themes of:

- Attitudes of staff: eg: “I think they have an attitude problem with compassion and understanding”;
- Mental health illness/issues not taken seriously: eg: “and even when I rang, ‘help me, help me, I can’t do anything, all I want to do is sleep’ it was just, ‘it’s your problem’”;
- Pathologising reactions to the system: eg: “my fighting the system, they saw as... more of my, what they classed as my mania coming out, but really, it was just my sheer anger.”;
- Individual interest/focus/recognition: eg: “If they’d taken the time to actually chat with me, get to know my personality...”;
- Future orientation/ hope for the future: eg: “I think also a sense of looking in the future ...let’s have some aspirations, let’s have some goals to work to.”

Holding these different components of the theme together is the common thread of a sense of person at the core. The way the staff, particularly, and the service, more generally, relate to them as a person, and attempt to meet their personal needs, is the focus of this theme.

### *High versus Low Quality and Completeness of Care*

This theme includes both in-patient and out-patient care, and represents discussion within the focus groups about whether the public mental health service provides the type of service consumers are saying they need. A strong under- current in the focus group discussions was that consumers see themselves holistically, with needs and requirements beyond the medical, or physical. Incorporated into this theme are these abstract ideas, as well as more concrete expressions made by participants relating to care needs. The following sub-themes are represented by ‘completeness of care’. These are evident within a context of the personal in the focus group discussions, and relate to a conveyance by the participants of who they are – a sense of identity:

- 
- Co-ordination of care: eg “a lot more coordination too. I’ve met several people involved in several people’s lives...the left hand has no idea what the right hand’s doing, so there’s a real conflict there for the person.”
  - Limitation of medical focus: eg “they’re just sort of giving the medication. They’re not coming back to the why’s or ‘well, how did this come about?’”
  - Immediacy and availability of help (including after-hours): eg “if a person rings up because they need help, they need help before it gets to the stage...there needs to be something immediate.” “somewhere to go, anytime of the day or night when you need company.”
  - Emotional support/someone to talk to/ counseling: eg “I think that’s absolutely critical, to feel that you can see a counselor”
  - Out-patient care/ follow-up: eg “but because they’re not actually residing in the hospital system, they forget about you.”
  - Out-patient resources: eg “there’s no safe, friendly place people can go and congregate, and learn to rehabilitate themselves...”
  - Mobile treatment team / crisis mental health team: eg “I also think the mobile treatment team’s pretty understaffed, and when they come around, you can just tell they are watching the clock, and have got somewhere else to go.”
  - In-patient care – environment: eg “I’ve been to [two inpatient units], and [one] is just a terrible place to go when you’re not feeling well. At [the other] the facilities are a lot nicer”
  - Rehabilitation/ activities (both in-patient and out-patient): eg “the main thing to improve would be to have diversional therapy, activities”
  - Family inclusion: eg “the thing my husband finds upsetting is that no one will talk to him. He’s sort of left out of the equation.”
  - Diagnosis: eg “Firstly I was told I was bipolar, ah, then, medication wise, they had me on a type of medication which I know is for a type of schizophrenia.”

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*With or Without Resources*

This theme captures discussion at a more general level about resource needs. These are comments that are not elaborated on by participants in the focus groups, for example comments like “more staff” or “funding”. The distinction between this theme and the above theme High versus Low Quality and Completeness of Care is that the theme of With or Without Resources represents discussion by participants that does not give context, and a personal link, whereas the above theme relates more closely to personal needs and a wholistic self.

*Involvement versus Lack of Involvement*

This theme captures the expressed desire by consumers to be included in service provision by the mental health service. Participants express concern for other consumers – perhaps experiencing similar issues to which participants have themselves – and a strong indication that they feel willing and able to provide support and services to other consumers. An example of this theme from the focus groups is provided in this statement:

I think as a community we should take responsibility to reach out to people and help each other. And maybe we can get rid of the stigma that other people have towards mental health if we still are helping each other as a group.

Not as strongly evident, however still discussed by participants, is the idea that they would like input into services. Rarely is involvement in their personal care planning explicitly mentioned. Some consumers discuss a need for the staff within services to spend more time getting to know them, their personality, or their needs. These discussions, however, have been included within the first theme, Valuing/Devaluing of the Person.’

### *Availability versus Inadequacy of Information and Education*

Lack of information is most often discussed by participants in the focus groups. This relates to a variety of areas of service provision, from lack-of information about medication, to lack-of information on admission to an in-patient unit. This theme also includes discussion of lack of information in an early-intervention context. Community knowledge and staff education also fall within the theme, which includes the following sub-themes:

- Lack of information provided to consumers by mental health services: eg “...but nobody told me I was supposed to have seen the doctor first..”
- Community knowledge/education: eg “people in the community, they’re still very ‘no, no’ – they don’t want to hear about it, they don’t want to know about it...”
- Mental health service staff and auxiliary service staff knowledge/education: eg “so it’s whether the community health...needs a lot of education to the people who are actually at the grass roots level...”

### *Positive and Negative Medication Experiences*

This theme relates to discussion of medication by participants. The sub-themes represented by ‘Positive and Negative Medication Experiences’ include:

- Over/mis-medication: eg “they were drugging me so harshly, I was actually physically falling over and banging my head”
- Side effects: “if I get good medication, I don’t have the same aches and pains, my sleep is better, and my appetite less erratic.”
- Positive impact: eg “when they found the right medication for me, I did really well”

It appears that for participants in these focus groups, experiences with medication can range from extremely negative to very positive, and these experiences are central to their overall experience with the service, and recovery.

Table 12

*Themes from Analysis of Focus Group Responses from Participants in Study 1*

Theme	Description	Example from text
Isolation and community (latent)	This theme relates to discussion of isolation and loneliness, as well as consumers relationships with community.	“..I used to be isolated. And that socialisation is a first step of walking again. You know how you say you’ve got to crawl before you walk.”
Power and disempowerment (latent)	This theme is most frequently expressed in terms of the power of others, particularly mental health professionals, with a sense of personal disempowerment.	“you don’t have a voice with them”
Valuing versus devaluing of the person. (manifest)	Incorporates the notions of respect and dignity or lack of them	“I think they have an attitude problem with compassion and understanding”
High versus low quality and completeness of care (manifest)	Represents discussions within the focus groups about whether services provide the type of service consumers’ are expressing they need. Includes a notion of wholistic self.	“They’re just sort of giving out the medication. They’re not coming back to the why’s, or well, how did this come about?”
With or without resources (manifest)	Relates to general comments about resource needs in services.	“more staff”; “funding”
Involvement versus lack of involvement (manifest)	Captures the expressed desire by consumers to be included in service provision by the mental health service, and concern for other’s experiences.	“I think as a community we should take responsibility to reach out ...and help each other”

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Availability versus Inadequacy of Information and Education (manifest)	Relates to discussion about the importance of adequate provision of information, across a broad range of areas, as well as the need for greater education.	“nobody told me I was supposed to have seen the Doctor first...”
Positive and Negative Medication Experiences (manifest)	Represents discussion by participants about medication, and the various negative and positive aspects of it.	“when they found the right medication for me, I did really well.”

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## Expanding the Picture of Being a Consumer of Mental Health Services: Results from Interviews with Mental Health Consumers

The 10 themes derived from analyses of the interviews are displayed in Table 13, and discussed in more detail below. The order of discussion of these themes does not reflect an order of importance – either conveyed by participants in interviews, or judged in analyses.

### *Acceptance versus Stigma*

This theme represents participants' direct discussion of stigma as an issue for them within mental health services, within the community, and for themselves. It appears from these interviews that stigma is a broad issue, which the consumers we spoke to generally consider important for mental health services to address.

With reference to mental health services themselves, one participant says: "I think that's the big one about them not treating me like a person." As this participant goes on to tell her story, she relays this experience:

a doctor from out of here stopped me in the middle of the street and pointed to all his offsider doctors - trainee doctors – pulled up my sleeve and...said 'look at this stupid girl, cutting herself' and ...that devastated me. (Participant 11).

Another participant comments: "As far as stigma from the service providers: profound...we are seen as not being able to make decisions ...good decisions..." (Participant 15).

The three aspects of stigma discussed seem related, however the largest area discussed by participants is stigma faced within the community, both the general community and personal community, such as family and friends. Participants spoke about experiences with neighbours, friends, their children's friends, at TAFE,



[Technical and Further Education college] with tradespeople. The range of discussion was broad within the sub-theme, however one of the common threads was the link made between experiences of stigma and the need for education and information, and a view that stigma arises out of a lack of understanding.

Self- stigma is a further aspect of stigma identified by some participants. This sub-theme connects quite closely to the sub-theme ‘living with it’ of the theme ‘All of Me’, as well as the isolation pole of ‘Isolation and Community’. This sub-theme captures participants’ discussions about their own stigma, expressing reactions towards themselves. One participant says: “self-stigma is very hard to get over...” (Participant 15) another participant describes her experience saying: “I know I had a stigma towards my own illness, and that caused me to just – I seized up emotionally for two years...” (Participant 18).

#### *Highly Informed and Educated versus Poorly Informed and Educated Environment*

This theme, relating to information and education consists of several sub-themes, indicating specific issues highlighted by participants. These are Access/lack of access to information; Reliability of information; Being/ not being informed; Education of staff; Education of the community.

Information is most commonly discussed by participants in terms of its lack, by participants in the interviews. This deficit relates to a variety of areas of service provision for example lack-of information about medication:

I think it’s either a lack of information that the source has themselves, or laziness on the part of a drug company...just sort of flogging out what they...want to push...I think it’s the source of information is so hard to get – like if I went to my psychiatrist, then you would expect your psychiatrist to ...hand it out but he’s not going to. Not - none of them that I’ve been to

handed out information on lithium, or ...perhaps that should be more accessible to them...” (Participant 12).

Another participant tells her story:

...that’s very poor, just being put on a new medication. I wouldn’t even [have] had the name of it written down unless I specifically asked someone to write it down for me. I still don’t have any of the list of side-effects that it causes...if you want any information about medication you’ve got to specifically ask for it, you know what I mean? Then you are lucky to get it!” (Participant 18).

Other participants discuss the lack-of information they experienced about their diagnosis: “I wasn’t given enough information about my own illness which was a bit of a disappointment...” (Participant 14). Many participants discuss seeking information beyond the mental health service, for example several participants refer to borrowing or buying books, and watching television programs and useful videos. Often, these participants discuss their choice to do this as relating to the lack of access to information within services: “I’m not given any information by my psychiatrist, I go and look it up on the net myself.” (Participant 20).

It seems that for most of the participants in the interviews, information is very important. However, some participants indicate they are given little information, but they are currently satisfied with this state. In addition, while most participants express a lack of accessible information, particularly through services, a few participants indicate that they feel there is ample information available.

While often it is clear from participants’ discussions why information is important to them, some participants’ accounts help explain this further. One participant says: “reading about it, and finding information about not only

agoraphobia but schizophrenia as well, I think it's helped me to see reality a lot clearer, and therefore it's made me more well..." (Participant 22).

Another participant says: "some of the information I was supplied with by the Mood Disorders Unit really helped me to get an understanding." (Participant 8). It seems that information is one means by which participants come to greater self understanding, one of the sub-themes of 'All of me'.

Raised by the discussions of access to information, or lack of access, although not explicitly referred to by participants, is the question of how reliable is the information received? This seems to be a particular issue for information about medication, which frequently seems to come from pharmaceutical companies.

Another aspect of the theme relates to being informed, as distinct from accessing information, however similarly is most frequently raised in stories in which participants feel services do not keep them informed. While the distinction can at times be fuzzy between these two aspects, being informed links back to a more personal focus, relating to consumers own care and role in the service. For example, one participant commented: "No one told me I was going to the Magistrate until the day, the actual Magistrate, which I think was a disadvantage to [me]..." (Participant 14), and another: "No one could tell me whether [if] I walked out the gate, whether I could be certified or not certified, or whether I could just go home..." (Participant 16). Another participant shared this story:

...I was in the acute ward, and I got very unwell, I blacked out. I was in this room, but I can't remember what happened after that, but I woke up the next day in the room...I had a big lump in my arm, and I thought they must have given me an injection...I asked the nurse... and she said no...They said 'no, you didn't have an injection' but I felt the lump in my arm.

(Participant 21).

It seems that both having access to information and being informed contribute to empowerment, as one participant comments:

The empowerment of the consumer is really important, I think it's really important that the mental health services staff give consumers the fullest information possible about treatment, about diagnosis, about prognosis, about how long they're likely to be on medication, about how long they're likely to be in the service... (Participant 7).

Education of both staff/professionals and the broader community also fall within this theme. Most frequently, participants' suggestions of areas that education needs to occur is in understanding – both staff and the general community – of what it is like to experience a mental illness. Related to staff education is the implication that staff knowledge and expertise affects consumers' experiences. Some participants made reference to the level of expertise or knowledge mental health staff had. For some participants, staff's knowledge or expertise clearly affects their experiences with services. For example, one participant, speaking about a staff member he found to be very good, said: "...he's very knowledgeable and he can help you get back on track." Another aspect of community education is specifically that of carers and family members, and how services can keep them informed and educated. As the theme *Supportive or Unsupportive of relationships with community, family and other consumers* indicates, relationships with family are crucial for many participants.

### *Power and Powerlessness*

The theme of Power and Powerlessness runs through participants' interviews, connecting to many of the other themes identified in the transcripts. This theme relates to a personal sense of having power or control, or not. Most frequently it is the

powerlessness side of the theme represented. At times powerlessness is discussed in the context of struggling with experiencing symptoms, or living with a mental illness, for example: “Particularly in the early days, particularly in the very early days I ... was extremely sick and I lacked, I lacked power over my life...” (Participant 17)

However, the theme is also reflected in participants’ stories of struggling with the system, running through much of participants’ discussions about all aspects of their experiences with services. At times participants discuss feelings of powerlessness directly:

When I was admitted ...that was powerless. You were part of it, a number that was lining up. You slept in a dormitory, you had no freedom outside, and you were pretty heavily drugged, so that’s powerless. You were pretty much under... the thumb, and sometimes as a consumer consultant, even today, I feel powerless... (Participant 12)

Frequently, as in the above example, a sense of powerlessness is closely related to experiences in hospital:

...you are shuffled from one place to the next...and the whole admission process is very clinical and ...last admission she said to me ‘I think you had better send some of that jewellery home’ ...I think it was just so she didn’t have to write it down but you know, if you have to take off your jewellery and, you know what I mean? Like, it’s part of me. (Participant 20)

The powerlessness aspect of this theme is particularly evident in stories told by participants about being heavily medicated, to which Participant 12 (above) refers. Another woman discussed her experiences of being heavily medicated when having to attend legal hearings:

I was doped up to the eyeballs...I wasn't in a position to represent myself, which I think if you are going to be put before a Magistrate, you should be given an opportunity to be in a state of mind where you are not doped up to the eyeballs so that you can put your side [of the] story through.

(Participant 14)

Indeed, when discussing any experiences related to medication, many interview participants convey a sense of disempowerment where doctors are the experts and have the balance of power to make decisions, to even choose whether consumers are heard or not:

Well, first of all the psychiatrists do not listen...the medication had the most intolerable side effects...the medication made it impossible to live...they would put me on this medication, they would put me on it and they would put me on a community treatment order and I'd have to suffer it for three months...

(Participant 18)

Although less frequent, some participants identify a feeling of power. One participant relays her experiences of coming to feel empowered:

when I did this consumer education course, I found out, you do have rights...that's when the first mental health strategy was coming through, and all these new programmes were coming out, you know. So I was sort of involved...I did become empowered by all this stuff, because I got employment...they had a consumer support meeting...and they employed me to run the meeting...and I was also getting involved in my own area, going to meetings and things.

(Participant 21)

This participant goes on to describe herself as "an empowered consumer" later.

Another participant's account of isolation also clearly conveys a sense of personal power:

the fact that we isolate ourselves, we are quite capable of changing that, we are quite capable of... if we really want to, it's not easy to do but you can force yourself to get out and mix with people and um, at first it's very difficult but you can actually get out and mix with people, and improve your life...

(Participant 17)

One of the striking differences between discussion of feeling powerless versus feeling powerful from these participants, is that a sense of powerlessness is so frequently connected to the manner in which service operate, and how staff and other community members interact with consumers. However, when participants spoke about feeling a sense of power, more often this reflected a personal achievement, or a journey that had little to do with empowering services – indeed at times it was despite disempowering experiences with services:

I worked out how to be powerful, it's taken...eighteen years to work out how to deal with doctors when you are going to see a magistrate, because for eighteen years ...I was powerless in that situation because the doctors had the upper hand the whole time, and whatever they said would go in that magistrates hearing and this is where it all happens, in the magistrates hearing. And the consumer is completely intimidated in that situation ...it's taken me this long to get on top of it, and I realised that the doctors would just have a list of all the complaints and they would just say "this patient has this, this, this and this, and that this patient does this, this, this, and this, and therefore she's sick" and I thought, well right! I'm going to have a list of positive things that I do out in the community and see what they can say to

that, so I just listed all the things that I had, my responsibilities at home and in the community...the magistrate let me out in about three or four days. So that was when I experienced power. (Participant 18).

### *Consumer Involvement versus Lack of Consumer Involvement*

This theme captures the expressed desire by consumers to be included in all aspects of service provision by the mental health service. Participants express concern for other consumers – perhaps experiencing similar to participants. For example one participant says: “...the more consumers can contribute, the more we have a say in how services will affect our health...and our brothers and sisters who suffer the same problems...”(Participant 14). Another said: “I was getting well, and finding that I could get employment, and it was also what I wanted to do, help other people, other consumers who’d been through the same thing...” (Participant 21).

Participants refer to the positive impact involvement has for them personally: one thing I did find that was good for me was, as a consumer, I actually started doing odd jobs around the place and got paid, ended up with a pay thing but I was also invited to meetings, staff meetings and all that and learnt, learnt a lot about how professionals treat us patients and I was also allowed to have a say in things... (Participant 14).

Other participants refer to the mutuality of consumer involvement: “...it’s mutual, or should be a mutual thing, like helping each other, helping somebody else is a way of helping yourself...” (Participant 17).

A strong current within this account is the need for more consumer involvement – at all levels:

What we need more of is consumer driven services to be worked, to start in the acute area as an introduction and- ...getting to know people and then



gradually increasing as you move back out again into the community, and moving away from the psychiatric nurse in a mental health team in a community – needs to more focused by people who understand...

(Participant 15).

Another participant, talking about the same issue said, that “much more involvement of consumers helping consumers...” (Participant 17) is needed. Another consumer also raised this issue:

Ideal service[s] would have consumers working for the service, there’d be consumers working as case managers or assistant case managers, and in an in-patient service there would be consumers talking to you, offering you, listening to people’s experiences, providing information and support.

(Participant 7).

An aspect of this is the sense that services are still frequently resistant to greater consumer involvement. One participant spoke of her own experiences, saying:

I can remember one service worker...he said ‘well, you’ve got what you wanted’ and I said ‘what do you mean?’ and he said ‘well, they just passed it at the meeting, you keep, you just keep barking and barking and barking, so they said, ‘just shut her up and give it to her’. So I thought, well, if it has to take that, it has to take that. But I think things will come easier in time. If you project twenty years ahead, hopefully there will be a very well known system in place and consumers ...will be part of the normal system. (Participant 12).

Another participant spoke about the struggles he faced:

It’s patronisation...all we are ever told, we are seen as not being able to make decisions or, when I say decisions...good decisions: coping with, managing

large sums of money or running our own services. We are set up to fail and when we fail they say ‘told you so’. (Participant 15).

Another participant went further, discussing the need for education of consumers if consumer involvement is going to work:

...you’ve got to have educated consumers, we need to have the proper training...to be able to do that, because you don’t suddenly become an expert at consumer participation. And the staff people don’t know what consumer participation’s about, they don’t understand what it is... (Participant 21).

While she does not explicitly make the link, implied is also the need for training of staff and professionals about consumer participation or involvement to make it a reality, which further adds to the discussion about resistance of staff and services to consumer involvement.

One participant sums up clearly what seems to be the underlying reasoning behind the theme of ‘consumer involvement’, which many participants do not state as explicitly: “I think it’s very important because they are the ones that have the in-depth information...about their own experiences and they can help other people that have experienced it...” (Participant 26). Another participant explains: “including consumers would be a big plus, because you get a more sensitive and responsive service.” (Participant 7). Several participants directly link consumer involvement in services to creating a sense of hope for consumers. For example, one participant spoke about his involvement in visiting other consumers in hospital:

Telling them that there’s things outside that you can go to if you’re interested, and also that I’m just one of them, and you can come back and talk to people as well if they’d like to, and just know that we’re all part of, kind of an

understanding group. And just that there's hope for people...

(Participant 5).

Another participant said: "being able to meet other people who had similar problems as myself and being able to talk to them, I was given a bit of hope that things could actually improve." (Participant 8).

### *Optimal and Appropriate versus Inadequate and Inappropriate Medication Experiences*

This theme relates to discussion of medication by interview participants, representing the importance for many participants' medication plays in their experiences with services, and their personal experiences of illness and recovery. The sub-themes include: Side-effects of medication; Finding medication that works; and Professionals working 'with' me regarding medication. Frequently participants discuss the negative aspect of side-effects of medication, and the importance of finding a medication that works for them. Connecting strongly with the themes of relationships with staff, and power and powerlessness, is the sub-theme of professionals working with me regarding medication. Several participants highlighted the relationship with professionals around medication issues. For some participants, an important feature of finding a medication that worked for them was having professionals who listened to their opinion, who worked with them, rather than over them, to find medication that worked. For example one participant said: "I did have a good doctor- when there comes a time where I said 'I'd like to try something else'...the doctor's quite willing to let me experiment...and [I] ended up on [medication name] which works quite well..." (Participant 2)

### *High versus Low Service Quality System*

This theme relates to the many issues raised in the interviews about services at a system or organisation level. Sub-themes captured within this, comprising “system issues”, are the physical Environment, Safety; Privacy; Follow-up; Continuity of care across services; Accessibility of services, both in-patient and out-patient; Activity in hospital; Initial contact with a mental health service; and Staffing. Many of these relate back to resource issues and funding for mental health services broadly, however all are highlighted as relevant and important to consumers of the services, with participants indicating that each of these issues impact on their experience with services.

### *Responsive or Unresponsive to Consumers*

This theme captures discussions within interviews of the need for services to be responsive to consumers; that the purpose of mental health services is to *serve* consumers. At the core of this theme is the question of who decides what is needed for any consumer, how choices are made, and whose needs are being met in the process. For example, some participants described the process of services helping to identify their needs at a particular time: “...they’d work out whether I needed to be in hospital or whether I just needed time out.” (Participant 11). Other participants highlighted experiences, where despite their sense that services should be aiming to best accommodate consumers, often this was not the case: “the timing of things [is] because staff want to do something else, and it’s not actually oriented towards consumers.” (Participant 12).

One of the strong components of this theme is choice, or consultation, and from this perspective links specifically to two other themes, relationships with staff,

and power and powerlessness. One participant spoke about having decisions made for him, rather than being consulted about: “what I was looking for, or what would suit me, it was pre-perceived and arranged without any consultation.” (Participant 15). This example demonstrates that for services to be responsive to consumers, a range of complex components is required. The same participant goes on to say later in the interview: “They don’t ask you what you want, they find what they can give you, get you, and you’ve got no option...”.

While some of the stories relayed by consumers in our interviews represent examples of services being responsive to them, more strongly conveyed is frustration at finding services that are not responsive, and some examples represent quite basic, concrete, situations. For example, one participant spoke about being given inadequate amounts of water to take her medication with and having to address this; participants spoke about information being displayed in in-patient units in positions that were inaccessible, particularly for consumers whose vision may be affected by medication.

### *Satisfying versus Dissatisfying Relationships with Staff*

Relationships are an important aspect of participants’ experiences, and how these are facilitated, or not, by mental health services. Relationships with staff appear to be central to many consumers’ experiences of the services. Participants refer directly to the attitudes of staff with whom they have interacted, but their accounts also refer to different behaviours of staff, which indicate either generally positive or negative attitudes towards consumers. An important aspect of attitudes in the discussions of participants was communication between themselves and staff: the communication behaviour of staff indicating their attitude towards consumers.

The positive and negative attitudes of staff were discussed, however, there was a predominance of negative attitudes in participants stories. As one participant

indicates, which seems reflective of many of the consumers' discussions, it is unusual "to get someone that is prepared to show personal interest in a consumer rather than treatment is just another pipe coming through the service..." (Participant 15).

Participants spoke about doctors being "cranky at me at taking up the bed and the time" (Participant 1) in hospital. Doctors who "didn't talk to me about anything" (Participant 1); having staff "yell at you... 'go back to sleep', you know they'll sort of act as if they're – it's awful because it's sort of like, they've got the power...". As in this example, much of the discussion about staff attitudes, particularly negative attitudes towards consumers, overlaps with the theme of Power and powerlessness. One participant described feeling threatened by staff in hospital: "they said '...you're going to get in trouble soon, do you want to go back to the acute ward?' And they were threatening me with the acute ward." (Participant 21).

The theme of staff attitudes also links to that of 'Availability versus Inadequacy of Information and Education', particularly in situations in which participants speak about not being given information and not being kept informed. Participants' discussions indicate that some staff appear to hold the attitude that consumers do not need, or have the right, to be informed.

Despite the predominance of stories about more negative staff attitudes, some were about positive attitudes: staff being "very supportive – and they do follow up if you need... follow up care they will see you every day if you want them to." (Participant 16). Whether participants speak about experiencing positive or negative staff attitudes, it is clear from these discussions that staff attitudes are integral to their experience of any service. As one participant says: "there are things that they have to do, but I think it goes back to attitude and how... people do it." (Participant 20).

*Supportive or Unsupportive of Relationships with Community, Family and Other Consumers*

Relationships with community, relationships with family, and other consumers are all highlighted as relevant areas to mental health service provision. Participants in these interviews seem to indicate through their conversations that part of the role of services is to facilitate these three types of relationships – each being important to their experiences and recovery.

Relationships with community can be captured in the sub-theme of isolation and community, which falls within this theme. This sub-theme captures the dual aspects of connectedness: a sense of isolation and a sense of community. This theme weaves in and out of participant's discussions, connecting with many of the other themes identified. A variety of aspects of isolation and community are raised within the discussions. Participants talk about isolation as a feature of illness; something they do because they are unwell.

The illness makes you isolate, because you are unaccepted – how can I put it - ...you self isolate because you feel that you are not – everyone's thinking or talking or reacting to you, which is a little bit of paranoia... (Participant 15).

The overwhelming nature of isolation is captured by another participant: "...even though there might be stacks of people around you, you can still be – you can still be alone amongst stacks of people...you can isolate yourself amongst thousands of people..." (Participant 17). Other participants refer to isolation as a "big problem" and as an ongoing experience and issue for them.

Isolation is tied to experiences of mental illness for participants. One participant comments: "I don't go to people's places any more since I've been ill, I just stay at home..." (Participant 29); "...it's when, because of the depression or the

medication, you're not actually able to get off the bed and go and interact with people..." (Participant 8). While for some, isolation reflects their own actions and responses, others discuss isolation as something forced upon them by others: "It's like people don't really want to meet me..." (Participant 34). Several participants talk about becoming alienated and isolated from friends through the course of being diagnosed with a mental illness: "when I was in hospital, in the psych unit...I lost quite a few friends..." (Participant 21).

Isolation is also a feature of some participants' discussions of services themselves. One participant relays an experience with a community team:

I haven't had much to do with community health...since they didn't call through to me, I've felt very isolated now from that, thinking 'what are they – what is it that they actually think of me' sort of thing...you know, do they think I'm not that bad to worry about?"

Describing his sense of isolation further, he goes on to say "you do feel a form of isolation, because it's like, 'who do I tell, who do I tell?'" (Participant 4). Many participants also spoke about feeling they are not listened to by staff and service providers – another aspect of isolation for consumers in relation to services.

Connecting with the community also takes varied forms for the participants. For some, isolation is overcome within mental health services, particularly through contact with other consumers, and here the theme overlaps closely with that of consumer involvement, particularly participants' discussion of the personal benefits and mutuality of being involved:

"Interviewer: what alleviated your isolation was actually meeting other people?

Participant 12: it was just me identifying..."



For others, it is through connection with other parts of the community that isolation is overcome or challenged:

I go to TAFE [Technical and Further Education college] now – didn't used to go to TAFE. I stayed at home all day everyday, and I found that's when, you know, I was having bad thoughts and getting upset, and wondering what to do with my life, so I'm at TAFE now...I don't have that problem...

(Participant 32).

Another participant spoke about church as her place to connect with others:

"you know how hard it is to find friends in the community, but I go to a church, and I have friends through the church, I've found some wonderful support through that..."

(Participant 18). As one participant says, connecting with the broader community was important for her, "rather than just being in this mental health tunnel" (Participant 16).

Participants in the interviews have discussed a broad range of experiences with isolation and feeling a sense of community, however one of the clear messages within the discussions is that for most participants, a sense of community – connectedness – is important to their recovery, and mental health. As one participant stated: "our enemy is isolation" while "friendship is the key to mental health" (Participant 17). Implied is that services need to accommodate this experience, and facilitate connectedness in its variety of forms, both within and beyond services.

Relationships with family were also highlighted in relation to experiences with services, and linking this with the discussion above, is another form of connectedness. The role family play in supporting them was discussed by some participants, while others discuss the need for families to be provided with more information and education. At the core of these discussions, however, is the importance of having supportive and successful relationships with family for many participants, and the

implication that services have a role to play in facilitating these relationships. While information and education is one role for services in facilitating these relationships highlighted by participants, another is in-patient units that are more amenable to accommodating family members – either visiting, or staying in the case of single parents with young children.

Relationships with other consumers are highlighted by many participants as central to their experiences of services and recovery. Participants used phrases like “consumers for consumers” and recalled experiences such as:

it was the first time I talked to anyone who had a mental illness, and another girl with children about the same age as mine were and, it was like letting a bird loose out of me, and I thought...then that it was – I hadn’t realised what it was that was in me – it was identifying with someone else, but that you are not totally absolutely bonkers – but something inside of you could have happened inside someone else... (Participant 12).

Experiencing commonality appears to be strengthening for many of the participants, and through relationships with other consumers, as the example above indicates, many consumers feel their experiences validated and understood.

Some participants, while highlighting the importance of relationships with other consumers, indicate that simply meeting other consumers is a major issue, particularly in rural areas, where development of these relationships is hindered: “that’s one of the situations we have to overcome to be able to introduce consumers to consumer...that is the main stumbling block to consumers helping themselves or helping each other...yeah, finding each other...”(Participant 17).

The aspect of fostering hope, discussed in the theme of consumer involvement above, is relevant here also. For many participants, meeting other consumers at different stages of recovery provides both needed comfort and hope:

they have been extremely comforting...someone with a problem that I've had and who, who are doing so well and have been through the ropes and know the ropes...to come and see me and talk to me and be involved in my problems, and interested in my problems...it's very comforting...

(Participant 18).

This theme intersects also with the theme of isolation and community – with consumer community being important to participants as was mentioned in discussion of that theme. The focus here, however, is on the importance of services fostering these relationships, creating opportunities and environments for consumers to meet and relate to other consumers.

#### *All of me versus me as an illness*

This theme was labeled “all of me versus ‘me’ as an illness” to capture the sense of person beyond mental illness, and specific diagnosis, conveyed by participants in the interviews: in other words the whole person. Several sub-themes make up this overall theme. These we have labeled: ‘Me’ beyond medication and diagnosis; Diagnosis; To be seen as a person; Living with a mental illness; Opportunities to achieve/master; Work force retraining; Exploration of issues for self – self understanding; Cultural sensitivity; Learning skills to help manage symptoms and life. Each of the sub-themes identified here indicate a different aspect of the whole self, discussed by participants in the interviews, together accumulating to represent an expression that mental health services should be dealing with each person as broader than their diagnosis and/or illness.

Me beyond medication and diagnosis we use to represent discussions by participants where they identify their needs for services to reflect and cater for more than just medicating:

I say this over and over, is the fact that these doctors give you all the medication you want, but there's no safe alternative, like say cognitive – I mean it's there, cognitive behaviour therapy, but you have to find out yourself about it. (Participant 10).

Another participant expresses her frustration at the limitation to a focus on medication that she experienced within services: “I find that highly abusive, when there are alternatives that have proven to be successful...” (Participant 2). This type of discussion is repeated throughout these participants' stories. The consumers to whom we spoke also talked about other aspects of themselves as being important; coming through their stories was the need for consideration of them as a whole, unique, person:

“The only time I was ever asked if I had a child was on my last admission...” (Participant 20);

“Yeah, the ideal service, I guess, would see accommodation...other things, right, one place where you can get your psychiatric care, sport...a centre for a combination of things...” (Participant 26).

“I was also on the contraceptive pill when I was there and they didn't give it to me...that freaked me out...” (Participant 32).

Another aspect to this theme, raising the issue of consumers as ‘whole’ people, is captured in participants' discussions about living with a diagnosis of mental illness. Participants made comments such as:

“I think, I feel all the time that ‘till the end of life I'll be battling this..” (Participant 1).

“My whole life was just embarrassing...I was overcome by this thing that I was in...you don’t want to get out of the house...” (Participant 10).

“it destroyed everything else I had, it destroyed the relationship to the point of total destruction – total destruction. Lost my career because of it, it’s just a ...slippery slope to hell, not fast but a very slow slippery slope...” (Participant 15).

When I’m depressed I have not power to then get up and do things, I feel lost and then when I’m in mania I can’t control myself to actually do things...you do lose a lot of control...and then when you’re normal, you just feel a bit desperate...you’ve done all these things. It’s very hard. (Participant 22).

The sub-theme diagnosis captures participants’ discussions about diagnosis and the role this has played in their experiences with mental health services. Several participants spoke about their frustration with not being diagnosed, or with continual re-diagnosis. Participants also spoke about the difficulty to move beyond a diagnosis given, within the service, indicating that their experiences have demonstrated that other staff they encounter remain tied to the diagnosis they’ve received – even when their symptoms and experiences do not fit this diagnosis.

Participants also discussed having opportunities to achieve, or master something. These stories are varied in terms of what is being achieved, however a common core is the sense of achievement expressed by participants, and the importance of these opportunities being created and provided by mental health services:

...we made beads and I made the most beautiful pair of beads, you know. People comment they look really nice, and that was something really constructive that we could do...that’s something really, really precious that if you can make... something in hospital that you can take home, you would

think, ‘well, look, I was sick when I made that, look how lovely it is’ you know. When I was in [hospital] when I first got sick, we made pottery, you know I’ve still got the bit. It wasn’t as nice as the beads but it was something that, you know, you can say ‘yes, well I was unwell when I made that, and it’s precious’ (Participant 18).

The same participant also speaks about the morning meetings held while she was in hospital, presenting these as another opportunity to learn and *achieve* “each person gets a turn sometimes to lead the meeting, and that’s really something that’s...a learning experience, you know an achievement to lead a meeting. That was good.” She also suggests for her these meetings helped “you learn to speak up for yourself”.

Other participants talk about the importance of social activities and outings, seeing these as opportunities to achieve:

that outing I used to go on, it was something that I started to look forward to, because I found that the ten-pin bowling was something I was actually quite good at, and I got to a point from that – that’s when I first started to understand that I could get well... (Participant 4)

He goes on to explain that the service helped him get coaching, by accessing funding through disability services for this. This participants’ story is a clear example of the importance opportunities to become capable, or for a person to explore their own capabilities, can be in terms of recovery and hope. The variety of topics or examples raised in the interviews indicates that opportunities to achieve or master are important at a variety of levels – addressing a range of options - within services.

Linked to this sub-theme is that of workforce retraining opportunities.

Participants also spoke about the importance of work, and their needs:

I would like somewhere where they actually start retraining you to enter the workforce...I would like something like that where I could just get transition back into the workforce gradually, a support network – you know someone to support you in looking for the work, help you find the work, finding employers... (Participant 14)

Participants' stories also raise the issue of consumers wanting to understand themselves better, with several participants recalling important experiences that helped them come to a greater self-understanding, saying things like: "Before I didn't know what was happening to me, whereas I do now, so I cope with it...and I know how to look after myself..." (Participant 21). This is a further sub-theme within "All of Me", again linking back to the overall concept of each consumer being unique, much more than a diagnosis. One participant spoke of an experience opening "my eyes up to what's valuable in my life", another spoke about the new understanding she had of herself after completing a course offered by a mental health service covering things like relaxation and cognitive behaviour techniques. She recounts the way her approach to herself has since changed as she's come to greater self-understanding. Another participant spoke about her desire to have help in understanding herself further: "To be able to talk to someone about the actual hallucinations and um, how they affect you emotionally. To sort of let you understand what is happening to you." (Participant 2). While this also highlights a deficiency in the services available for this participant, these words convey a strong need to understand herself and her experiences more fully. Another participant says: "Not only to see when you're not well, but to understand what's going on with you when you're not well, yeah, I think it's played a big part for me..." (Participant 21).

Closely related to the sub-theme of self-understanding is the final sub-theme of “learning skills to manage”. Often, the two are interlinked in participant’s stories, with self-understanding leading to knowledge of what new skills may be necessary, or acquisition of new skills. The opposite link is also represented, where learning new skills to help manage symptoms leads participants to a greater, or new understanding of themselves.

Each of the threads – the sub-themes – of *All of me versus me as an illness* relate to participants’ sense of what could help, and what they’ve already experienced as helpful, in moving on their journey of recovery.



Table 13

*Themes from Analysis of Interview Responses by Participants in Study 1*

Theme (with sub-themes)	Description	Example from text
<u>Acceptance versus stigma</u>	Participants discussed stigma within services, within the broader community, and within the person/self stigma.	"I know I had a stigma towards my own illness - I seized-up emotionally for two years." (self-stigma)
<u>Highly informed and educated versus poorly informed and educated environment</u> <ul style="list-style-type: none"> <li>○ Access/lack of access to information</li> <li>○ Being/ not being informed</li> <li>○ Reliability/unreliability of information</li> <li>○ Education of staff - Staff expertise/knowledge</li> <li>○ Education of community</li> </ul>	As the sub-themes listed indicate, this theme is multi-faceted. From the personal perspective of having access to information & education or not, and being kept informed, to identifying the education of staff and community as important issues.	<p>"if you want any information about medication then you've got to specifically ask for it,...then you are lucky to get it !"</p> <p>"No one told me I was going to the Magistrate until the day, the actual Magistrate, which I think was a disadvantage to [me]..."</p>
<u>Power and powerlessness</u>	This theme relates to a personal sense of having power or control, or not. Frequently discussed in terms of powerlessness or the power of professionals. When a sense of power or control was discussed, often this seemed to be despite the system.	<p>"When I was admitted... that was powerless, you were part of it, a number that was lining up... you had no freedom outside"</p> <p>"I was doped up to the eyeballs...I wasn't in a position to represent myself"</p>

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Consumer involvement versus lack of consumer involvement

This theme is about the expressed desire to be involved in all aspects of service provision. Participants refer to the positive impact involvement has for them, and the mutuality of involvement, as well as its relationship to hope. A strong undercurrent is the need for more involvement.

“I was getting well, and finding that I could get employment, and it was also what I wanted to do, help other people, other consumers who’d been through the same thing...”

Optimal and appropriate versus inadequate and inappropriate medication experiences

- Side-effects
- Medication that works
- Working ‘with’ me regarding medication

This theme relates to discussion of medication by participants, representing the importance for many participants medication plays in their experiences with services, and their personal experiences of illness and recovery. The 3 sub-themes are listed.

“I did have a good doctor- when there comes a time where I said ‘I’d like to try something else’...the doctor’s quite willing to let me experiment...and [I] ended up on [medication name] which works quite well...” (working ‘with’ me re medication)“the timing of things [is] because staff want to do something else, and it’s not actually oriented towards consumers.”

High versus low service quality system

- Environment
- Safety
- privacy
- Follow-up
- Continuity of care across services
- Accessibility
- Activity in hospital
- Initial contact
- Staffing

This theme relates to numerous issues raised in the interviews about services at a system or organisation level.

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Responsive or unresponsive to consumers

This theme captures discussions within interviews of the need for services to be responsive to consumers – that the purpose of mental health services is to *serve* consumers.

“They don’t ask you what you want, they find what they can give you, get you, and you’ve got no option”

Satisfying versus dissatisfying relationships with staff

- Staff attitudes- good and bad
- Communication with staff
- Being listened to/ being heard

Relationships are an important aspect of participants’ discussions, and how these are facilitated, or not, by mental health services. Relationships with staff appear to be central to many consumers’ experiences of the services. The three sub-themes listed make up this theme.

“to get someone that is prepared to show personal interest in a consumer rather than treatment is just another pipe coming through the service...”

“very supportive – and they do follow up if you need...follow up care they will see you every day if you want them to.”

Supportive or unsupportive of relationships with community, family and other consumers

- Isolation & community

Relationships with community, relationships with family, and other consumers are all highlighted as relevant areas to mental health service provision. Participants in these interviews seem to indicate through their conversations that part of the role of services is to facilitate these three areas of relationships – each being important to their experiences and recovery. A linked aspect of this is the sub-theme of isolation and community.

“The illness makes you isolate, because you are unaccepted – how can I put it - ...you self isolate because you feel that you are not – everyone’s thinking or talking or reacting to you, which is a little bit of paranoia...”

“that’s one of the situations we have to overcome to be able to introduce consumers to consumer...that is the main stumbling block to consumers helping themselves or helping each other...yeah, finding each other...”

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All of me versus me as an illness

- ‘Me’ beyond medication and diagnosis (physical, alternatives to medication etc)
  - diagnosis
  - to be seen as a person
  - living with a mental illness
  - opportunities to achieve/master
  - exploration of issues for self – self understanding
  - cultural sensitivity
  - work force retraining
  - learning skills to help manage symptoms & life
- 

This theme was labeled “all of me” to capture the sense of person beyond mental illness, and specific diagnosis, conveyed by participants in the interviews: in other words the whole person. Several sub-themes make up this overall theme

“I say this over and over, is the fact that these doctors give you all the medication you want, but there’s no safe alternative, like say cognitive – I mean it’s there, cognitive behaviour therapy, but you have to find out yourself about it.”

“...we made beads and I made the most beautiful pair of beads, you know, people comment they look really nice, and that was something really constructive that we could do...that’s something really, really precious that if you can make... something in hospital that you can take home, you would think, ‘well, look, I was sick when I made that, look how lovely it is’ you know.”

## Conclusions

In this chapter, I have presented the themes that resulted from analysis of focus groups and interviews conducted with consumers of public mental health services. Eight themes interpreted by analysis of focus group responses have been presented, followed by ten themes identified through analysis of consumers' responses in interviews. As I described in the previous chapter, the interview method was designed specifically to build on the understandings we had developed from participants' in focus groups. The questions asked in interviews were guided by the themes our analysis of focus groups had produced.

Comparing the two sets of themes, one immediately striking difference is the description of latent themes in the focus group analysis, but not in the interview themes. In interviewing, we openly asked about these latent themes, thus rendering them explicit. This meant that whereas in focus groups, most often the constructs labelled as latent themes underlay more manifest content (although, at times they were explicitly described), during interviews, the Consumer Researchers gave voice to these constructs in the questions posed, and so participants addressed these clearly in their responses. In analysis of the focus groups, I found that the latent themes were the major threads that tied the six manifest themes together. In analysing the interview data, we found a more complex web of connections between themes, which I have tried to indicate in the descriptions above.

Comparing the two sets of themes, those from focus groups with those from interviews, what is found is strong commonality between the two, however, while some themes from focus groups remain as stand-alone themes in our analysis of interviews (for example, Power and Disempowerment/Powerlessness), others have been subsumed into broader, and more rich and wholistic constructs (for example,

Community and Isolation became incorporated as a sub-theme into Supportive or unsupportive of relationships with community, family and other consumers in the interview analysis). This is what would be expected from the design of Study 1, where interviewing was specifically aimed to build on the understanding of being a consumer developed from analysis of focus groups.

In the following chapter, I will discuss the results presented here, and how they fit within the broader literature. I will also discuss the implications these results hold for mental health service evaluation, provision, and policy. These results will be considered again in Chapters 12, 13 and 14 of this thesis, at that stage in conjunction with the results from Study 2, in order to address the remaining research questions I have posed. In these chapters, I will compare results from Study 1 with those from Study 2.

## CHAPTER 9

EXPERIENCES OF BEING A CONSUMER OF MENTAL HEALTH SERVICES:

STUDY 1 DISCUSSION

The research question Study 1 aims to address is: *What are the experiences of being a consumer of public mental health services?* In this chapter I will discuss the results of Chapter 8, exploring the answer they produce to Research Question 1. In doing this I will consider how these results resonate with other literature that describes consumers' experiences. I will also explore how these results add to the body of literature to create an overall picture of consumers' experiences. In particular, I will consider other literature that describes consumers' experiences with mental health services and explore the implications the results presented in the previous chapter have for consumer evaluations of mental health services, as well as service policy and provision.

#### What are the Experiences of Being a Consumer of Public Mental Health Services? Using the Themes from Focus Groups and Interviews to Answer Research Question 1

The eight focus group themes and ten interview themes presented in Chapter 8 provide a rich and layered description of the experiences of being a consumer of mental health services. Consumers' discussions about services raise themes relating not just to service provision but broader life. The context of living with a diagnosis of mental illness, and a range of normal human struggles, cannot be separated from their experience of using mental health services. Other studies have found similar results (Gordon, Ellis, Haggerty, Platz, & McLaren, 2004; Gordon & Pere, 2003; Horsfall, 2003; Kilkku, Munnukka & Lehtinen, 2003). Additionally, consumers in this study identify wanting and needing a range of services they find unavailable to them through the public mental health system, consistent with other research conducted in the field (Brems et al 2004).

One of the questions raised by this issue is whether public mental health services *should* be catering for this breadth of issues? Or, what is the role of a mental



health service? Different view-points result in different answers to this question. From a medical model perspective, many of these domains are not within the scope of public mental health service provision. Nelson et al (2001) argue, however, that domains that relate to consumers' access to valued social resources, like housing, education, and employment should be within mental health services scope, but that, given the traditional paradigm which underpins the field, social policy needs to be changed to provide for this factor. Siggins Miller Consultants (2003) also argue that, from an outcomes perspective, services should be accountable for the range of outcomes viewed by consumers' as relevant, whether or not these are currently defined by services as their focus. These authors note research into "spontaneous recovery" in depression and alcohol dependence as supportive of this stance, stating that this literature demonstrates that changes in life circumstances, for example in housing, or education, can have greater impact on consumers' outcomes than more traditional therapy, such as pharmacotherapy.

Australian policy, in the form of the most current National Mental Health Plan (Australian Health Ministers, 2003) places mental health within a population health framework. The Plan states: "this framework is based on an understanding that the influences on mental health occur in the events and settings of everyday life." (p. 9). It says that a population health framework:

takes into account the complex influences on mental health, encourages a wholistic approach to improving mental health and wellbeing, and develops evidence based interventions that meet the identified needs of population groups and span the spectrum from prevention to recovery and relapse prevention. (p. 4).

From a population health framework perspective, and the stated priorities of the Australian National Mental Health Strategy, public mental health services *should* be playing a role relevant to all of the themes raised in focus groups and interviews: whether this is through direct intervention or through effective linkages with other sectors and organisations. If a genuine promotion, prevention, and recovery orientation is to be adopted, all of the issues raised by consumers in this research need to be considered, and adequately addressed in mental health care.

Many of the consumers we spoke to in focus groups and interviews still felt they were not being heard, and are not respected by the mental health services they have used. Consumers in this research came from a range of geographical areas, and were not all interacting with the same service. It appears that this is experienced across services. The most current Australian National Mental Health Plan 2003 – 2008 (Australian Health Ministers, 2003) supports this stance, in highlighting consumer participation as one of the outcomes related to the priority theme:

*Strengthening Quality.* The plan states that:

Consumers and carers report that there have been increased opportunities for participation in policy and planning, particularly at a national level. However, participation at other policy and planning levels, and participation in service planning and delivery across the spectrum of care from promotion and prevention to recovery, has not yet been achieved. Further work is required to ensure that meaningful participation by all consumers...is realised. (p. 24).

While participants in focus groups and interviews did mention some positive experiences and features of services, overwhelmingly their stories were negative. These provide support for the claim made in the above quotation, suggesting that participation in service delivery is still not being achieved for most consumers.

Other research findings support the themes found in focus groups and interviews presented in Chapter 8. A range of studies have been conducted using qualitative methods to explore consumers' experiences and views of services. These studies provide insight into how consumers' perceive and experience these services. A summary of the domains or themes found in a range of these studies is presented in Table 14, compared to the interview themes from Study 1, reported in Chapter 8.

Consistent language and conceptual groupings are not used across the studies presented, which makes comparison somewhat difficult. This is likely to be due, at least in part, to the range of methods used in analysis of qualitative data, and is also evidence of the interpretative, and data-driven nature of analysis involved in much research. To honour the stories of consumers, and present findings in their language, differences are likely to continue between conceptual groupings and language adopted to label themes in qualitative analyses. What is clear, however, is a strong commonality of themes across the studies, despite having been conducted in a range of countries.

Experiences of power and powerlessness, mostly in the form of lack of control, run through the themes presented. It is evident as an explicitly labeled theme by Goodwin et al (1999). The first two themes presented by Johansson and Lundman (2002) relate intimately to issues of power and powerlessness. Wallace, Robertson, Millar and Frisch (1999), state, when discussing the theme of partnership in their study that participants conveyed a sense of being "at the bottom of a hierarchy, weak, without choices and forced to do things because they are told" (p. 1150). In the analysis presented by McCourt (2000) power or powerlessness is implicit in the theme *Choice and current living situation*. McCourt says that most participants expressed

general satisfaction with their current living situation, although saw themselves as having little choice in the move from hospital. Consumers, like Unzicker (1989), also talk about the powerlessness experienced in her interactions with mental health services, and other studies also raise issues relating to a sense of empowerment, power and control (Siggins Miller Consultants, 2003).

Relationships with others: staff, family, other consumers, and the general community, is another theme consistently found across the studies, either explicitly or implicitly. For example, while Johansson and Lundman (2002) do not report a theme titled 'relationships', the themes of being respected as an individual, and being protected and cared for immediately relate a social, interactive, context. Other research, for example, the study by Allen, Carpenter, Sheets, Miccio and Ross (2003), examining what consumers say they want and need during a psychiatric emergency, also clearly highlights relationships with staff as central for consumers. Davidson and others' (Davidson, Haglund et al, 2001; Davidson, Stayner et al, 2001) too, highlight the importance for consumers of inclusion in the community – underpinned by relationships with others.

Stigma is also clearly a noteworthy experience that many consumers face, evident throughout the literature. Murphy (1998), for example, describes her own adult experiences living with a diagnosis of schizophrenia, and the pain caused by stigmatization. Schulze and Angermeyer (2003) describe results of focus groups carried out to explore stigma from the subjective perspective of people with schizophrenia, relatives and professionals. Participants in their focus groups spoke about the impact stigma has in their lives, in terms of interpersonal interaction, public images of mental illness and the consequences in terms of treatments offered, structural discrimination, and access to social roles. Their findings demonstrate that

the: “discrimination and disadvantages encountered as a consequence of schizophrenia reach far beyond the sphere of direct social interaction.” (Schulze & Angermeyer, 2003, p. 309). Knight et al (2003) also found in their interviews with six consumers that stigma is an enduring problem. Similar to the interview themes in Study 1, these authors found stigma was evident both at public levels, and as self-stigma.

In addition to the studies summarised in Table 14, other studies with more specific foci have been conducted the results of which not only resonate strongly with those presented in Table 14, but also help explicate some of the inter-connections found between the themes presented in Chapter 8. For example, Wood and Pistrang (2004) explored consumers’ experiences of an acute mental health ward focusing specifically on feelings of safety. Their analysis resulted in 10 core themes being identified, which fit within three broad domains, which are: Patient interactions; Staff behaviour and attitudes; and Non-consensual treatment. While these domains are clearly reflective of the authors’ specific focus on safety, there is overlap with themes of: Satisfying versus dissatisfying relationships with staff; Supportive or unsupportive of relationships with community, family and other consumers; as well as power and powerlessness from the interviews.

Another relevant example is a study conducted by Kilkku et al (2003). These authors examined the meaning of information giving to consumers’ experiencing first episode psychosis. The themes that emerged from their qualitative study include: Information from the experience of psychosis; Relief; A sense of connectedness; When provided by other consumers; Worthlessness; Confusion; and finally, Coping and confidence.

Table 14.

*Comparison of Main Themes or Domains found in a range of other Qualitative Studies, focusing on Consumers' Perceptions and/or Experiences of Mental Health Services, with Study 1 Interview Themes*

Authors & date	CEO-MHS themes from interviews, presented in Chapter 8	Fallon (2003)	Johansson & Lundman (2002)	McCourt (2000)	Goodwin, Holmes, Newness & Waltho (1999)	Wallace, Robertson, Millar & Frisch (1999)
Origin	NSW, Australia	Manchester, UK	Sweden	London, UK.	Shropshire, UK	Canada
Focus	Consumers' views and experiences with services	Lived experience of people with borderline personality disorder in contact with psychiatric services	Consumers' experiences of involuntary psychiatric care	Consumers' views of residential projects	Consumers' views of in-patient services	Consumers' and families views of mental health services
Themes	Acceptance versus stigma					Individuality
	Highly informed and educated versus poorly informed and educated environment				Information	
	Power and powerlessness		Being violated by intrusion on physical integrity and human value  Being restricted in autonomy		Power and control  Hospital as prison  Institutionalisation	

Consumer involvement versus lack of consumer involvement		Being outside and not seen or heard	Arrangements for consultation and user participation		Partnership
Optimal and appropriate versus inadequate and inappropriate medication experiences				Medication	
High versus low service quality system	The service response  Travelling through the system		Leisure and social activities  Personal and project finance	Non-tangible environment  Tangible environment  Rules and policies	Quantity and quality of care
Responsive or unresponsive to consumers					
Satisfying versus dissatisfying relationships with staff	Relationships	Being protected and cared for  Being respected as an individual	Views about staff	Respect  Caring and sympathy	
Supportive or unsupportive of relationships with community, family and other consumers					

	All of me versus me as an illness	Living with BPD		Choice and current living situation	Relaxation and activities Practical help Talking, counseling and listening	
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Nelson et al (2001) examined what empowerment means, and the relationship between personal empowerment and social power. In their study, they conducted focus groups and in-depth interviews with consumers involved in a community mental health system undergoing considerable change, featuring a move to a more empowerment-based philosophy and/or practice. They found three key elements of empowerment, which emerged as necessary to recovery that they suggest are essential elements of service provision within mental health. These were:

1. Access to substantive resources like jobs, housing, and money that improve quality of life, stability and self-esteem;
2. Ability to control ones own treatment plan, choose services and avoid coercion; and
3. Meaningful relationships, and participation in and control over, the agencies that provide mental health services.

Nelson et al (2001) observe that assessment of effectiveness of services has relied heavily on measures of hospitalisation and reduction of symptoms as outcome indicators, and suggest that: “these criteria reflect a focus on ‘mental illness’ rather than on mental health” (p. 137). Their findings are very similar to the messages conveyed by participants within our interviews and focus groups: reflected in themes such as *All of me, versus me as an illness*, *Power and powerlessness*, and the various themes about relationships that emerged in the two sets of results.

Jackson and Stevenson (2000) examined what people in contact with mental health services need nurses for. They held a number of focus groups, with 13 different groups, three of these groups were specifically with service users. Their findings are

grouped around a core theme of “knowing me, knowing you”. While Jackson and Stevenson related three sub-categories, “the three me’s”, what is of most interest here are the four dimensions identified within these sub-categories. Jackson and Stevenson relate these dimensions as depth of knowing, power, translation, and time, and these resonate strongly with a range of issues raised in the focus groups and interview themes and sub themes, particularly the themes of *Power and Powerlessness*, and *Satisfying versus dissatisfying relationships with Staff*.

The themes from focus groups and interviews presented in Chapter 8 also link closely to the recovery and wellbeing literatures. The basic assumptions of a recovery-focused mental health system were described in Chapter 3. Four studies exploring recovery or wellbeing from consumers’ perspectives are presented in Table 15.

Relationships again feature strongly in all of these studies. Mead and Copeland (2000) stress the importance of relationships – both in terms of peer support and professional support – in their discussion of what recovery means. Themes of stigma and acceptance connect closely to the theme of dignity which emerged from Svedberg, Jormfeldt, and Arividsson’s (2003) study; as well as carrying through several of the themes presented by Tooth, Kalyanasundaram, Glover and Momenzadah et al (2003). There is close linkage between the themes presented in Table 15, and the theme: *All of me versus me as an illness*, presented in Chapter 8.

#### Implications of the Findings for Consumer Evaluation of Mental Health Services

As discussed in Chapter 2, one of the most common approaches to including consumers’ views in mental health service evaluation has been the consumer satisfaction survey (Clarke, 2000; Milne, 1987). Consumer satisfaction surveys, however, have been criticised as being tokenistic attempts to include consumers’

Table 15

*Review of Literature relating to Consumer Defined Recovery and Wellness*

Authors & date	Gordon et al (2004)	Svedberg et al (2003)	Tooth et al (2003)	Ahern & Fisher (2001)
Origin	New Zealand	Sweden	Australia	US
Focus	Domains that consumers, across cultures have identified as being important in terms of their mental well-being, identified through consultation with consumers in New Zealand, and comprehensive examination of the recovery literature	Consumers' conceptions of how health processes are promoted in mental health nursing	Consumer perspective on recovery from schizophrenia. Reporting factors most frequently reported by people as important in their recover	Major themes highlighted as forming a recovery and empowerment culture in the National Empowerment Centre's research into recovery
Themes	<p>Relationships, trust, connectedness, taha wairua/whanau, whannau/family support, social support, interdependence;</p> <p>Day to day functioning, coping and managing, including work (having the ability to work), taha tinanan;</p> <p>Connection to one's culture, cultural identity, drawing strength from one's culture, taha wairua;</p> <p>Physical health and health risks, taha tinana, includes alcohol and drug use, side-effects of medications, sleeping and eating;</p>	<p><u>Interaction</u></p> <p>To trust</p> <p>To feel mutuality</p> <p>To enter into a personal relationship</p> <p><u>Attention (paying attention to consumer as important individual)</u></p> <p>To feel noticed</p> <p>To feel the nurses' commitment</p> <p>To feel the nurse is accessible</p>	<p>Determination to get better;</p> <p>Finding their own way to manage their illness,</p> <p>Recognition of need to help themselves, having friends who accept them, negative aspects of medication,</p> <p>Negative impact of health professionals, accepting the illness, life disruption caused by illness was a life transforming experience,</p>	<p>Relationships</p> <p>Beliefs</p> <p>Self/identity</p> <p>Community</p> <p>Skills</p>

<p>Quality of life, life satisfaction, enjoying the environment, feeling alert and alive, able to enjoy pastimes/hobbies;</p> <p>Illness symptoms, taha hinengaro;</p> <p>Coping with and recovering from illness, self-managed care, staying out of the mental health system, understanding of illness;</p> <p>Hope, journey from alienation to purpose, reawakening of hope after despair;</p> <p>Empowerment, being in control, exercising choice, positive sense of self, self-determination;</p> <p>Spiritual strength, increased spirituality, taha wairua; resources, basic needs (eg: food, money, transport); and</p> <p>Satisfaction with services.</p>	<p><u>Development</u></p> <p>To gain hope</p> <p>To see new possibilities</p> <p>To have one's good qualities recognised</p> <p>To obtain knowledge</p> <p>To be confirmed</p> <p><u>Dignity</u></p> <p>To have the right of self-determination</p> <p>To feel respected</p>	<p>Friends affirming the person,</p> <p>Struggled with ability to recovery, affirmation received from support groups, achieving something was important, support from health professionals,</p> <p>Stigma hindered process, understanding illness was important,</p> <p>Pre-illness strength helped,</p> <p>Emotional support from family,</p> <p>Hospital did not help</p>	
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views, as they frequently ask questions based on professionals views of what is important in services, not those of consumers (Campbell, 1997; Perkins, 2001). One of the limitations of using methods which do not adequately approach issues relevant to consumers, it is argued, is reflected in the consistently high and stable levels of satisfaction found using such surveys, despite evidence which indicates that high satisfaction levels do not represent many consumers' realities with services (Clark et al, 1999; Lynch, 2000). More contemporary measures appear more frequently to include consumers, to some level either in item development, usually via focus groups (Howard et al, 2001; Lelliott et al, 2001; Meehan, Bergen & Steadman, 2002; Spear, 2003) or in item refinement (Eisen et al, 1999). A comparison of the issues dealt with by these tools with the themes outlined here indicates that these measures do not cover the range of themes participants spoke about in our interviews. Each of these measures revolves around a slightly different grouping of issues, overlapping with the themes reported here. Table 16 outlines the domains covered in these tools, as well as the CEO-MHS interview themes. None of these questionnaires individually, nor the measures in collection, however, include areas corresponding to the themes stigma; relationships with their community; all of me; power and powerlessness, and the factors addressed in some of these tools only partially correspond to the themes of information and education as well as system issues. Both of these themes encompass some issues not touched on in those existing measures.

Two research projects, one conducted in Australia by Siggins Miller Consultants (2003); the other in New Zealand, by Case Consulting (Gordon et al, 2004; Gordon & Pere, 2003), support this point. Both studies found that consumer outcome measures they

had identified through literature searches of national and international literature, did not adequately address the domains highlighted in their consultations with consumers. This gap between consumers' views and experiences and existing tools, indicates that inclusion of consumers' voices in service evaluation needs to be addressed.

I suggest that major influences on the depth of the themes presented in this research are the level of consumer involvement, and the nature of the qualitative approach used. Consumers' views were sought initially in focus groups, which guided the interview questions. Interviews were then an opportunity to build greater in-depth understanding of consumers' views of services, as well as gain new information. Using the focus group themes as a guide, the team ensured that interviews were based on consumers' perspectives, not professionals. The satisfaction scales and the other measures I refer to above, all included consumer input through focus group discussion. I argue that the addition of interviews, using focus group themes to guide questions, allows for far deeper understanding of issues, as well as opportunities for different perspectives to be raised.

Another important difference in the way consumers were involved in this Study was that Consumer Researchers acted as interviewers, which, I suggest, created a possibility for depth in interviews that may not have been possible with non-consumers' in this role. These results indicate that areas relevant to consumers' evaluation of services are more extensive than existing measures suggest or allow, and support the view that a qualitative component to any consumer evaluation endeavor may be necessary, if consumers' views are to be genuinely included (Avis et al, 1997; Crawford & Kessel, 1999).

Table 16

*Comparison of Domains from Contemporary Satisfaction Scales and CEO-MHS Interview Themes*

Survey / Instrument	CEO-MHS Interview themes	Consumer Assessment of Behavioural Health Services Instrument (CABHS)	Kentucky Consumer Satisfaction Instrument (KY-CSI)	Carers' and Users' Expectations of Services – User version (CUES-U)	Inpatient Evaluation of Service Questionnaire	Consumer Expectations, Perceptions and Satisfaction Scale (CEPAS)
Author		Eisen et al (1999)	Howard et al (2001)	Lelliott et al (2001)	Meehan et al (2002).	Spear (2003)
Origin	Australia	USA	USA	UK	Australia	Australia
Themes / factors	Acceptance versus stigma  Highly informed and educated versus poorly informed and educated environment  Power and powerlessness  Consumer involvement versus lack of consumer involvement  Optimal and appropriate versus inadequate and inappropriate medication experiences  High versus low service quality system	Access to care  Continuity of care  Provision of information  Interaction  Rights and confidentiality  Global evaluation (this scale additionally evaluates insurance	Environment  Affiliation/esteem  Growth/self actualization	Quality of interactions with mental health workers  Sense of alienation  Finance, daytime activities and social relationships	Staff-patient alliance  Satisfaction with environment  Satisfaction with treatment	Access  Respect  Reliability  Responsiveness  Empathy  Participation  Overall rating

	Responsive or unresponsive to consumers	plans).				
	Satisfying versus dissatisfying relationships with staff					
	Supportive or unsupportive of relationships with community, family and other consumers					
	All of me versus me as an illness					



The depth and range of the themes raised in this study shows that it is essential that evaluation research in mental health includes consumers' perspectives, but also extends to including consumers in the overall research work (Rapp et al, 1993). It is only by basing new methods and tools for evaluation on the experiences of consumers that inclusion of issues relevant to them will definitely be included in evaluation tools (Perkins, 2001; Rapp et al, 1993). This will also create genuine consumer participation in this essential aspect of services, as Australian and international policies – and consumers - demand. The scope of the themes from the interviews reported in this study indicates that consumers' views of what is necessary to consider in evaluation of mental health services is much broader, and far more complex than previous measures to include consumers' views have acknowledged.

#### Implications of the Findings for Mental Health Services: Policy and Provision

The themes identified through these focus groups and interviews indicate that, from a consumer perspective, policy is heading in the right direction. For example, the current National Mental Health Plan, 2003 – 2008 (Australian Health Ministers, 2003) has as one of its four key themes, improving service responsiveness, picking up specifically on issues of access to the broad spectrum of care, continuity of care, and support for families and carers. The other key themes in this plan also pick up on issues related to the themes from focus groups and interviews: full and meaningful participation opportunities, promotion of understanding within communities, and a recovery orientation. The Australian National Standards for Mental Health (Australian Health Ministers, 1997) also address a number of important areas overlapping with the themes from focus groups and interviews, for example: promoting community acceptance;

consumer participation; upholding of consumer rights; and a broad range of issues linked to delivery of care. While national policy certainly addresses a large number of themes raised in Study 1, I suggest, however, that much of the subtlety evident in consumers' discussions about the issues that are important to them in mental health services is still not adequately reflected in the national policy. Additionally, hearing the experiences and views of consumers during focus groups and interviews, it appears that provision of services often still does not match policy, or the requirements of consumers. The themes identified in Study 1 are highly consistent with the findings of a range of other studies exploring consumers' views of services generally, or their views of specific aspects of mental health services. These studies have occurred over a number of years. However, the same core themes are still raised by consumers using services.

There needs to be greater enactment of participation initiatives and a more wholistic approach to service provision, which must span across the range of services available. One of the challenges to effectively implementing policy is the range of professionals involved, who come from different philosophical, epistemological and ontological perspectives. More effort is clearly required to build on empowerment as an underlying framework for services. Service provision should not be considered without a wholistic framework: the themes presented demonstrate that use of services does not occur in isolation for consumers, it interacts with every part of their lives. The themes presented in Chapter 8 not only represent much more than symptoms or a simple view of mental health services as purely medical; but also present a complex interwoven story. Each theme links with others; and some of the themes presented permeate most others.

Consumer participation should be more closely tied to quality improvement cycles within mental health services – the experiences and views of consumers should be directing service change and development (Consumer Focus Collaboration, 2000; Epstein & Shaw, 1997; Phillip & Stewart, 1999; Wadsworth & Epstein, 1996<sup>b</sup>). As the findings presented in Chapter 8, and other researchers demonstrated, while participation may be occurring, and research gathering consumers views of services is being conducted, often this is still not being tied back to continuous service improvement initiatives. This is further supported by findings presented in an evaluation of consumer participation in Victoria's mental health services (Service Quality Australia, 1999). Nationally, and at a NSW state-level, there is no clear policy that details a consistent approach to consumer involvement in service evaluation and improvement.

### Conclusions

In this Chapter I have placed the results from Study 1 focus groups and interviews within the context of the experiences of consumers of public mental health consumers, and discussed the implications these results have for service evaluation, policy and provision. In the next chapters I describe the second study of this thesis, which is dedicated to focusing on the experiences of consumers becoming researchers. Once the method and results of Study 2 are presented, I will return to considering the results discussed here further, within the context of the experiences of mental health consumers becoming researchers.

## CHAPTER 10

### EXPERIENCES OF BEING A CONSUMER RESEARCHER: STUDY 2 METHOD

Study 2 focuses more specifically on what it is like for consumers to become researchers and attempts to address Research Question 2: *What are the experiences of being a consumer researcher?* specifically, as well as providing information which will help address the remaining three research questions (see Chapter 6). In this chapter I will describe the methods used in Study 2, for conducting focus groups and interviews with consumers working on the Consumer Evaluation of Mental Health Services (CEO – MHS) project team to better understand their experiences of becoming researchers.

### Participants

Participants in Study 2 were consumers working on the CEO-MHS project, and included nine Consumer Researchers (CRs), and one consumer representative from the CEO-MHS Management Committee. Participants were already employed in their roles with the CEO-MHS project when they were invited to participate in this study. Initially, I informed them about my research at a general team meeting, providing written information and consent forms for them to take away. I stressed the voluntary nature of consent in both the verbal and written information provided to CRs at this point, particularly because of the relationship that had developed over the prior two years between the participants and myself. One Consumer Representative from the Management Committee chose not to participate in the research; however, all CRs from the team who were actively engaged in work at the time chose to do so. One CR participated in only one interview. This was the first interview in a sequence of two, as described later in this chapter. He did not withdraw his consent, however, took leave of absence from the research after completing the first interview. The data collected at this interview were included in the analysis conducted.

Demographic data were collected from participants after they had participated in the interviews and focus group for Study 2, and close to the end of the CEO-MHS project. Participants were encouraged to complete only those questions that they felt comfortable answering, given that while confidentiality was assured, anonymity could not be because of the relationship between participants and the author. Six men and four women participated in Study 2, their ages ranging from 31 to 54, with a median of 41 years. Seven participants were born in Australia, while two had been born in England, and one participant was born in Sri-Lanka. This participant was, however, of British origin. At the time when demographic information was collected, participants reported being engaged concurrently in a range of other work, in addition to their Research Assistant positions. These other work roles included:

- Mental health clinician;
- Mental health worker- Community Development Officer;
- Consumer rehabilitation assistant and Retail sales assistant/bookkeeper;
- Consumer coordinator for art exhibit for people with mental illness, and a free lance artist;
- Consumer rehabilitation assistant (relief position);
- Mental health representative, and volunteer;
- Volunteer [in mental health service work program];
- Music recording, performing, university study: Sound composition and production;
- Lawn mowing; and
- Car washing, and cleaning.

Additionally, participants reported a variety of previous occupations, which they had engaged in before employment as CRs. These included:

- Nursing;
- Public servant;
- Language teacher;
- Laboratory technician: 1968-81 and 1987-90;
- Electrical fitter: 1990;
- Cadet draftsman 1987-89, encyclopaedia door-to-door sales 1989, Sales/birthday party organiser 1999, Commissioned artist 1999-present, Radio operator 2001-02, Switchboard operator and clerk, 2000;
- Cleaner, handyman, file clerk, boy Friday, laboratory assist, factory worker; storeman; packer; shop assistant;
- Factory work, Sales – shoes and toys, Framing toner, Cake-packing, Waitress, Kitchen hand, Bistro attendant, “Wine Wench” [*sic*], Sales assistant;
- Factory work, Restaurant work, Antiquities; and
- Naturopathy, nurses-aid, waitress, cleaner, storeroom packer, door-to-door sales, postal clerk.

Participants’ income ranges are shown in Table 17. One participant chose not to respond to this question.

Table 17

*Income Range of Study 2 Participants (n=10)*

Income Range	Percentage
\$0-9,999	40%
\$10,000 – 19,999	20%
\$20,000 – 29,999	20%
\$30,000 – 39,999	0%
\$40,000+	10%
No response	10%

Participants reported having first sought help for emotional and psychiatric problems in a range from 3 to 29 years earlier. The median was 16.5 years earlier. Five participants reported having had contact with public mental health services, as a client, in the two months prior to completing the demographic surveys. The number of times these five had contact with a service during that 2-month period ranged from 2 and 20 times. One participant accessed private mental health services in addition to public services, while the other nine participants reported only accessing public services. Another participant, however, reported that she was also in the process of arranging services with a private facility.

Eight participants had been admitted to an acute psychiatric ward in the past, while two had not. Of these eight participants, they had experienced a range from 2 to 10 admissions, with the median number of admissions being four. Table 18 shows the percentage that had voluntary and/or involuntary admission experiences. Two



participants had been admitted to hospital during the period of their employment as CRs. One reported having two admissions during this time, while one did not provide details.

Table 18

*Type of Admissions to Psychiatric Ward of Study 2 Participants (n=8)*

Status	Percentage
Voluntary patient	37.5%
Involuntary patient	37.5%
Experienced both	25 %

Participants reported a range of diagnoses, as displayed in Table 19. While one diagnosis for each participant is reported here, several participants reported progressive and changing diagnoses. For example, one reported their diagnoses progressing from Schiziphreniform, Psychosis, to Paranoid Schizophrenia. Another reported originally being diagnosed with Schizophrenia but more recently the diagnosis being changed to Bipolar Disorder. Eighty percent of participants reported that they currently take medication. One participant reported not being on medication, and one participant reported having made the choice to cease medication only a few months earlier. Previously this participant had been receiving medication by injection from a community mental health team.

Table 19

*Reported Diagnoses of Study 2 Participants (n=10)*

Diagnosis	Percentage
Clinical depression	10%
Bipolar disorder	20%
Schizophrenia (type not identified by participant)	20%
Schizophrenia (paranoid)	30%
Post natal depression	10%
Anxiety	10%

Participants reported having used a broad range of mental health service types and settings. Eighty percent had used acute inpatient services, and 20% had used extended care inpatient services. Several also reported having used hospital outpatient services; one had used drug and alcohol services. Sixty percent had at some time in their lives used community residential services, while 70% reported having used mobile crisis or emergency teams. Twenty percent reported using mobile case management services. Sixty percent had used social and living skills services, and 60% had also used community mental health clinics. Half the participants rated themselves as highly experienced in using public mental health services, 20% stated they felt moderately experienced, and 30% rated themselves as “a little” experienced.

Finally, participants were asked to indicate if they felt they had experienced any significant events as consumers of mental health services, during their employment as

CRs. Seven participants reported they had, two reported they had not, and one participant did not respond. Their responses are included below:

- Attending a national mental health conference in Canberra (The Australian & New Zealand Mental Health Services Conference, TheMHS)
- “I was very aware of just the amazing support network that is developing – particularly [non-government organisation CEO-MHS data collection occurred at]. It reminds me how living skills centres USED to be.”
- Seeing a psychiatrist every four months - treatment for depression
- Empowerment with doctors, nurses and staff
- “I decided I had had a long time of health, and felt that it was time to try going off medication, and doing things more naturally – came off medication in August 03, and also came off the methadone program in the months following this.”
- 1) “The birth of my first grandchild by my youngest daughter”; 2) Commencement of employment at [metropolitan public hospital] as a mental health clinician; 3) “medication changes that completely made my mood unstable and I landed in hospital”; and 4) “companionship from fellow CRs was great, as well as staff from UOW”; and
- reduced level of medication by 25%

### Procedure

Data collection for Study 2 consisted of a focus group and two semi-structured interviews. Both are described in greater detail here.

### *The Focus Group*

A semi-structured focus group was run, in which participants were invited to reflect on the themes derived from Study 1 interviews (see Chapter 8). They were asked particularly to consider if and how these themes resonated with their experiences working on the CEO-MHS project. Participants were posted a copy of the focus group questions several days prior to the group being held, so they had time to consider the issues that would be raised before the discussion if they chose. The questions used to guide the focus group are included in Appendix D. I facilitated the focus group, posing the questions, helping participants share the floor during the discussion, and making sure the questions were understood. Nine participants attended in total, eight of the Consumer Researchers, and the Consumer Representative.

The purpose of this focus group discussion was to bridge the understanding developed about consumers' experiences – as recipients of mental health services – with the experiences of consumers becoming evaluation researchers. I was interested to hear if and how the themes that had emerged from Study 1 related to the experience for participants in Study 2 during their work as researchers.

### *The First Interview*

Before their initial interview, participants were asked to complete a “snake” or “winding river” chart (adapted from Denicolo, 1996; Tjok-a-Tam & Denicolo, 1996; Pope & Denicolo, 1991). This method invites reflection on participants' lives (Denicolo, 1996) or a particular period and aspect of their lives (Tjok-a-Tam & Denicolo, 1996), with bends in the river or snake indicating critical incidents. Apelgren (2003) has noted

the similarities between this method and phenomenological methods for data collection, such as “annals” or “Life-story” techniques.

Participants were asked to reflect on their lives since becoming involved in the CEO-MHS project, visualising and drawing this period as a snake or river, with each turn or bend representing a critical incident or point for them within this period. To facilitate this process, they were provided with a template over which to draw their snake, which listed milestones of the CEO-MHS project. This template is included in Appendix E. Participants were invited to incorporate these milestones, or not, as they felt relevant. Therefore, they could use the provided milestones as ‘bends’ in their river, or allow these milestones to sit on other parts of their river (therefore being incorporated as smooth sections of the river, not bends), if they did not represent personally critical points.

During the interview, joint reflection on the ‘snake’ charts then occurred. Additionally, the Experience Cycle Methodology (ECM), as described by Oades and Viney (2000) was adapted, encouraging participants to tell their story of being involved in the CEO-MHS project, using the Experience Cycle as a guide for the interviewer in eliciting CRs stories. The adapted ECM questions developed for this interview are attached in Appendix F.

### *The Second Interview*

Before meeting for their second interview, I invited participants to complete two self-characterisations. Firstly, an adaptation of the original instructions was provided (Kelly, 1955/1991), asking them to write about themselves, in the third person, as they were when they first became involved in the CEO-MHS project. When their first characterisation was returned to me, I provided them with the second set of instructions.

The second self-characterisation invited them, using the standard instructions, to write about themselves at the present time (Kelly, 1955/1991).

The second semi-structured interview was conducted once participants had completed both self-characterisations. This interview commenced with a discussion based on a set of questions derived from Epting, Probert and Pittman's "Let's Just Say" method (1993). These questions can be seen in Appendix G. Then joint reflection on participants' self-characterisations occurred. During this reflection, I invited each participant to discuss their characterisations, asking for elaboration and/or clarification of any points in the stories about which I felt uncertain. I also invited them to relate anything further they wanted, if they found any sections they felt they would like to elaborate on, or clarify. Participants were also asked about the differences between the person in both; and strengths and weaknesses. Once participants had given their reflections, I then talked about differences, strengths and weaknesses from my perception when reading the characterisations, and then I invited participants to, if they wanted, comment on my reflections.

The objective of this discussion was to identify meanings used to make sense of their processes of becoming researchers, as well as any emotions accompanying this transition, by asking CRs to discuss the themes within their self-characterisations (see Androutsopoulou (2001) for discussion of self-characterisations and narrative).

### Analysis of the data

The focus group and interviews were recorded then transcribed verbatim, with permission from the participants. The focus group data were analysed using the themes

from CEO-MHS interviews, as outlined in Chapter 8, which had been used to guide the discussion. A qualitative, reduction approach was adopted to analyse these data.

Qualitative analysis of the interview data was conducted, using Interpretative Phenomenological Analysis (IPA) in an attempt to understand the experience of becoming researchers for the consumers involved in the project. This method was consistent with the analyses conducted in Study 1, as described in Chapter 7. An overall list of themes was derived from this analysis.

Verification of the themes, in an early form, occurred in an additional focus group discussion. All participants were invited to attend, and seven attended. During this session, I provided participants with a written list and description of 11 preliminary themes. I explained that the purpose of the meeting was to check if the themes, as they were developing, were reflective of their experiences, and captured the meanings conveyed by them during our interviews. I clearly explained to participants that the themes as presented were still under development not yet in their final conceptualisation. The themes presented to participants at this stage were: Job features; Project features; Learning; Self; Emotional experiences/reactions; Relationships; Context; Opportunities – expanding horizons; Playing an active role; Power imbalance and empowerment; and The unknown. Participants provided strong support for all of the themes, and offered further discussion and explanation of some of them.

A second verification of the themes occurred using a draft of the results chapter, presented here as Chapter 11. Eight of the ten participants were provided with a copy of the draft, and asked to suggest any additions or changes. I was unable to contact two participants at this time, due to overseas travel and relocation. I posed the five questions

we had used with participants in Study 1 during feedback, and invited them to mark any changes on the chapter itself if they wanted. I asked them to pay particular attention to those sections where I had quoted them, to make sure that they were comfortable for any quotes I had used to remain in the chapter.

The two levels of verification that occurred allowed an opportunity for participants to check that the themes, and their descriptions, were faithful to the stories they had relayed in the interviews and focus group discussion. These processes additionally provided them with an opportunity to add to, or clarify, any sections of the discussion they felt required this, and to view, and correct if necessary, the direct quotations - their voices - from the interviews and focus groups.

Four of the eight participants returned feedback to me, and I had informal discussions with another two of the CRs about the draft. Each of these participants stated that they felt the themes, as presented in Chapter 11, reflected their experiences. One participant responded: "I'm quite pleasantly exhausted and pleased at what you have written...I did enjoy reading our "metamorphosis" – I guess our real voices are being valued and heard." Another responded: "I was happy to read the comments by me and I think your summing up was fair enough. I appreciate having a reminder of my progress and thoughts concerning that progress. I think you did a wonderful job, Gillian. Thank you."

### Conclusions

In this chapter I have outlined the method used in Study 2 of this research. The results of these analyses are contained in the following chapter.



CHAPTER 11

EXPERIENCES OF BECOMING A CONSUMER RESEARCHER:

STUDY 2 RESULTS

In this chapter, I present the results from Study 2, which include themes from the focus group and interviews with Consumer Researchers from the CEO-MHS team. The focus group discussion was based on their reflections on the themes presented in Chapter 8, and the role, if any, these themes played in their experiences of becoming researchers. The interviews required participants to reflect on their personal experiences and journeys of becoming researchers. The themes, derived from analysis of the interview transcripts, are presented here.

In reporting the results from the focus group and interviews, I have relied heavily on excerpts from the transcripts to convey my participants' voices as much as possible. In presenting the results in this manner, my aim is to demonstrate clearly what my interpretations are based on, and achieve authenticity, as described by Manning (1997) in her first type of authenticity, fairness, which I have discussed in Chapter 6, and described by Fossey et al (2002) as one element of interpretative rigour. Participants in Study 2 were asked to choose a pseudonym for the presentation of results. I have used their chosen pseudonyms in the following account.

#### Results from Analysis of Focus Group Responses

The discussion held by the nine consumer researchers is presented, grouped around the themes that emerged from analysis of CEO-MHS interviews. The themes from that analysis were presented in Chapter 8. Overall, participants indicated that each of these themes held relevance to their experiences of becoming researchers, working on the CEO-MHS Project. Results from their discussion of each theme are presented here.

*Acceptance versus Stigma*

Some of the participants stated that being involved as CRs in the project helped them “defeat” stigma. For example, San said: “It gives you a purpose. And that purpose sort of defeats stigma in a way, because you’re doing something that’s - you can focus on.” San described the project as something that gives him a sense of purpose, which he feels boosts his confidence. Part of this related to the project playing a role in creating a focus in his life:

San: It sort of gives you something to do otherwise you’re wandering around doing nothing. You’re not doing anything for anyone else. You’re doing something for a purpose, it sort of adds up to self confidence.

For Ruth, the project helped defeat stigma because she felt she is seen as an “expert” in her role as a CR:

Ruth: Well for me, this type of work defeats stigma, because being experts in the area of mental health, and also being over-comers in the area of mental health as we are... We’re able to um, we’re branching out for a start by being used here in the university in this project, because we are experts, it boosts our self esteem. We’re not here telling people about our problems, and saying ‘we need help’. We’re here talking about the issues and contributing.

Gillian: Yep. So you feel it’s defeating stigma because you’re contributing in a positive way to the area of mental health?

Ruth: Yeah. We’re not here complaining, we’re here doing something about it.

Ruth found recognition and validation of her strength and journey of recovery, by taking part in the project. Ruth also described feeling pride in her role, and presenting this when she spoke to others outside of the team:

Ruth : Any time I've spoken about work, I've done it with pride. I've never felt I need to keep this 'hush hush'. And I've always used 'consumer research assistant' I've never left consumer out. No-one's ever questioned me, and said, 'oh, you're a consumer?' nobody. They've all been really excited for me.

San, however, described greater uncertainty about making his role clear to others, outside the project:

San: There's a lot that goes unsaid, like if you opened up to everyone that you met on the street, and you told them that you're involved with a mental health topic, they probably wouldn't see you in the same light.

Gillian: Yep

San: So I always keep that secret, and if I say I'm working at the university as a consumer researcher, people think you're gathering data on people going shopping, or something like that. I don't go into details.

Gillian: yeah

San: There's still a lot of fear there that if you open up you're going to get labeled.

These comments by Ruth and San highlight the importance, and interconnection, of their growing self confidence and their perceptions of stigma and acceptance.

Many of the team found the project played a dual role in their personal experiences of stigma: one that challenged them, sometimes from their perspective

increasing stigma, but also, at other times, helped reduce stigma. Taking on a role within the area of mental health research, specifically because of their experiences using services, in many ways pushed their identification as a consumer to the fore. For example, Ann, who worked concurrently in the mental health field as a clinician at the time, spoke about her experience as a CR:

Ann: Mine's been both positive and negative. I think with my work, because I work in mental health, some of my co-workers see it [working as a CR on the project] - the stigma actually increases because they see it as a lesser thing.

... and that impacts on you, because, I felt like at times I wasn't equal to them.

I'm academically equal to them, but as a human, there was this barrier that I found. At home, um, with [my husband] I found it more of a positive thing -

Gillian: Mhm

Ann: which has been really good. So it's sort of worked both ways.

Other participants related similar mixed experiences, in terms of how others perceived them when they have discussed their work on the project:

Walter: I agree with other people that some people, when you say you're doing the work, when you say your doing this project, and they say "who's it with" and you say the mental health service, people go "aah". It's like people have this negative reaction. They don't think that it's - it's not a positive thing. [It's like] there's something wrong with it, that it's limping along, or there's something you know, not "well" about it. But, beyond that, there have also been people who have been enthusiastic about whatever work that is being done, and saying that's great.

So, whatever positive work that's being done does help break down people's negative perceptions of mental illness though.

One researcher also spoke about how she attempted to use the work as a tool to gain status within her family and peer group. She found, however, that this was unsuccessful for her because the job was within the mental health field. Susan said:

It just shows me how deep stigma is, when um, you know, I'll say that I've got a job to family or friends, and it's "oh, that's very good, that's very nice". But with the mental health service "oh". And the stigma is that I can't get a job unless I'm assisted to in the mental health service. So even the having the job, you know, I'm sort of trying to use it to get a bit of status, um, they can sort of look down on it because it's an assisted position.

Later, she expands: "But it's a fine line. I was actually after status there, and it's a fine line between lack of status and actual stigma."

Participants also described the CEO-MHS project as something they see playing a role in fighting stigma more broadly:

Algernon: I guess the long-term view is that we will be judged in five years time [by] what's happened to the work that we've done.

Gillian: Mmm

Algernon: So all of us, the whole team, will be judged. And as consumer researchers, if we're going to make a contribution to developing that role, if we think our role's worthwhile, it's what happens to the tool, and the evaluation framework, and you're work [this thesis!] and what everyone thinks of that, and whether we've earned respect in - I don't know - all the communities we're

interacting with. That's the long term view... We can contribute positively to reducing that stigma if our work is received well. And that's how you break it down, by earning people's respect, you know. Provide a good role model, behave appropriately, all those sorts of things.

Some members of the team also spoke about how attending national conferences played a role in their perceptions regarding the project and stigma. The participants seemed to focus on their experiences of stigma in communities outside of the research team during the discussion, so I asked them to comment on a more internal perspective:

Gillian: most of what you've talked about so far is the issue of stigma outside of the project, so what are people's experiences with stigma inside the project? Has anyone got anything to say about that?

Mandrake: Well, yeah. I think the fact that the research project got off the ground, based on the fact that it was going to be a consumer evaluation merits some worth. In a sense it's recognised that consumers have got a valid voice and that they're experts in the experience of mental illness, and I think that outweighs - that's very positive as far as stigma goes. That recognition that we have an opinion, and we're heard, I think stigma doesn't get a look in.

Gillian: OK

Mandrake: That's my opinion.

While there was strong agreement between the participants that they felt that the project environment was explicitly "anti-stigma" they did relay some experiences where they felt some sense of stigma. For example, Ruth spoke of wondering, at times, as she attended the university if people she passed recognised her as a consumer: "and I think I wonder

how they'd treat me if they knew I was a consumer. Because people have smiled and that, and I think, well they don't realise I'm a consumer." Later in the conversation, stigma within the project was raised again, and through this discussion, the dynamic of perception and reality began to be explored in relation to stigma:

Algernon: I think the way Gillian, Kim, and predecessors- and Marie - I mean we're working in a mental health environment,

Gillian: Mhm

Algernon: And you just wonder, I mean I think everyone would agree that you've treated us with the utmost respect at all times, and we've felt that we've been valued, but does that transfer to another environment? I call it the cocooning effect, you know? I don't know if it's true or not, but um, you know, I think we've been treated very well here.

Isis: I feel we're sort of equal. We don't really have that label - I don't feel it anyway. I feel able to really be on equal footing, and I haven't experienced stigma in this at all. I've found it very helpful just to be able to feel on a level playing field, either one on one or as a group.

Ann: I think respecting where everyone is at any one time has helped too. You know, if someone's not well, we've all been through it.

Ruth: Now that I think about it, because I haven't really been giving it a lot of thought to be honest, I did feel a little bit of stigma at the very, very start, and possibly it was just within myself, but when I was first interviewed by - I can't remember who the first woman in the project, who was she?

Gillian: [suggests some names of earlier team members]



Ruth: [name] That day I felt she might have been looking down on me. When I was sitting there at [service], and she was interviewing me. Yeah, I felt a little bit then. She may not have, it might have just been something within me, because it was something new for me

Gillian: Yep

Ruth: But yeah, I did feel like I was a bit under the microscope, and I didn't feel comfortable answering the questions,

Gillian: Yep

Ruth: That's when I felt there might have been - I'm not saying that I'm right.

Gillian: That's OK, that's your perception. Did other people ever feel sort of early on that there were times when there was perhaps some sense of stigma within the project?

Isis: I'm, I'm - because I had never thought about the earlier stage because I'd thought we'd come so far, and we've worked with so many different people, and different people early on who aren't with us now. I felt oh, I felt not at that sort of level then, now that I think about it now that you've said that, I think, Oh, just a little bit, but yeah. Not now, but maybe earlier on, because you feel overwhelmed, and you think about academics, and you think "am I going to be - is there going to be stigma there?" It's uncomfortable then. I didn't even think about right at the beginning.

Ruth: I didn't even think of it until we were just sitting here.

Isis: When - the first day when we were sitting in this room with the PowerPoint, and they were talking about how to conduct an interview, and how giving out

personal information often makes you feel uncomfortable, I thought, I hope I'm not in that situation. I don't know if that's stigma, but it just made me feel a little uncomfortable.

Ruth: Yes. And even one day when we were walking down to the library, we were going there to do what did we do in the library that time?

Isis: Oh, the

Mandrake: Research? [indicating training in using database resources at the university library]

Isis: Research

Ruth: I felt a little bit then. I thought, oh, we're all in a group. I wonder if people will be thinking who we are - if they knew we were all consumers, you know?

### *Highly Informed and Educated versus Poorly Informed and Educated Environment*

Participants reflected on how being employed as researchers on the CEO-MHS project had increased their knowledge, and access to information. They highlighted a number of examples, such as having access to university library resources, and journal articles:

Mandrake: For example, writing the paper for TheMHS [The Australia and New Zealand Mental Health Services Conference] on collaboration, we were given you know, a list of papers that we could access, and we just had to pick our preferences and they were supplied to us. There was heaps of good material in that, and I think as far as information goes, there's been adequate, plenty. And it's been empowering I think,

Gillian: Yep

Mandrake: Yeah. It's been very good.

Gillian: Mmm

Isis: I know what you mean about the abundance of information. That has been fantastic. In that sense, it's good.

Walter: I agree with that too. I think that there's a lot of - I've learnt a lot that I wouldn't have learnt if I hadn't been involved in the project. There's been a lot of information that's been given out

Susan: And information takes the sting out of the stigma, and it does a lot of things.

One participant spoke about how her role as a CR gave her new insight into the difficulty for consumers whose first language is not English, and how difficult accessing information is for these consumers. She had not been thoroughly aware of their situations previously.

They also recognised, however, that at times having access to information, and learning how to use it was overwhelming and difficult:

Isis: I found the computer - when we went to the library I found that really overwhelming, because it was just journal articles and it was so technical, and I found that really hard, that information and education part, I found that really hard. Like we were sitting there, and I found myself looking around the room - I switched off. And I found that quite overwhelming.

Some CRs also spoke about how the information and education they had access to through the project expanded their horizons, and showed them a bigger picture of the mental health, and consumer movement:

Ruth: I've always done consumer rep work, and work in the rehab centre and things so I've sort of always confined myself to one area, well not one area, but just to that area. And then, seeing what's been done outside as far as academically and here and there, it's broadened my horizons or you know, enlightened me ... now I'm seeing the bigger picture.

Gillian: mmm. OK.

Ruth: It's interesting what other people are doing in the area of mental health.

Gillian: Ok, so it's broadened your perspective, of what you know about.

Ruth: Mmm

Susan: Yes, I found it interesting to see the bigger picture.

San: Being involved in the project, it's like, it's empowered me to like, yeah, see the big picture. And it's inspired me to look in new directions to meet my goals in normal life.

Gillian: Ok.

Ann: I think the big picture's fine, but my real joy has been the research itself, and how you actually do the parts of the research, and the benefits and what we're going to achieve out of it. Without looking at the outside, just specifically looking at the research we've done ourselves, and how that's progressed and changed.

And we've all changed outside of that, but the process of doing the research itself is really interesting, and it's really educational, and all the parts: going to the conferences, and doing interviews and whatever. But what actually is going to be the outcome of it all, that's what I'm interested in, as it progresses.

Participants reflected on the iterative and reciprocal nature of the information cycles within the project team:

Algernon: I think what we've been provided with is a lot of information, and we've be able to use our experiences to process that information, and give you more information about what we think, like in the developing of the Evaluation Framework, and that sort of thing

Gillian: Yep

Algernon: So I think we've provided our perspective, as a consumer, we've provided you with new information with that perspective.

Another aspect of the theme from CEO-MHS interviews was the aspect of being kept informed, slightly different to having access to information. I asked CRs to think about this:

Ann: I think we've been informed all the way through. If we need information we could ring you, you were always accessible, the team was accessible. I mean, you couldn't really criticise it at all. It's just all gone along as we've gone along, and it's been accessible and that's what we've needed. At times it's probably been difficult for whatever reason, for all of us.

Mandrake: I think yeah, that um, communication has been really valuable. What I've appreciated too is the amount of planning that goes into a session.

Gillian: Mhm

Mandrake: Yeah, and I think that's really great stuff. So you can look at the plan, and say, well, that's great, now we know where we're going, you know, it puts it all in perspective.

Gillian: yep

Walter: I think the follow up stuff to sessions was really important. I think some of the follow up stuff that we were sent after the sessions was really important, because I think there was stuff that we learnt during the sessions, but we didn't take our own notes, and it wasn't possible to absorb the whole session, so it was really important

Ruth: that's right

Walter: And made sense that it was followed up, and there was a certain amount of work that went into that.

CRs also commented on the personalised nature of communication within the team:

Walter: I also think the staff got to know us more as we went on too, so they were able to understand individual problems or individual things that were problematic, and deal with them -

Ruth: mmm, that's right

Walter: reasonably, you know, without causing more problems.

Ruth: mmm. We're not all treated the same, you know, you realise we're all different people, different personalities, different lifestyles and we are respected for that.

Gillian: Mhm. Is there anything more anyone wants to add about information and education in relation to the project?

San: the contact that I've been having with the project has been pretty supportive and encouraging as well. Always knowing ahead of time what's going to come up

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*Power and Powerlessness*

Participants in the focus group described power and powerlessness as an important issue in their experiences as Consumer Researchers, and discussed the mixed experiences of both feeling a sense of power or control, as well as feeling powerless, or out of control during the research process.

Mandrake: I, at different stages I've had different experiences. Like sometimes through the evaluation process, I felt a bit overwhelmed, because of the sheer volume of information and it's complexity.

Gillian: Yeah

Mandrake: Ah, and then other times, like at TheMHS [The Mental Health Services Conference of Australia and New Zealand], you know, that's really empowering. So it's the other side of the coin.

Gillian: Mmm

Mandrake: Yeah, so...the project, overall I think it has been empowering. It's broadened my perspective, I've seen other issues involved in mental health, so it's broadened my perspective and helped me appreciate where other people are coming from ... and that's empowering, to have greater understanding.

San: also, I've been given new skills, like listening skills and learning how to operate a tape recorder I guess, and interviewing skills.

Gillian: mmm. And so for you having those new skills has been empowering?

San: Yep.

The experience of conducting interviews was a time where some CRs felt varyingly, a sense of power, and at times felt powerless:

San: The skill of having a non-judgmental attitude was pretty important. Because ah, sometimes interviews gave you a bit of power, you know, directing all the questions to the consumer. It was sort of like you had status and the other person didn't, or you had understanding and the other person didn't, and the whole point of the conversation was to keep it sort of a balance, so you could get data.

Gillian: Yep

San: and it was sort of like - if the interview didn't go well, it was sort of like you were a bit powerless, 'cause there was nothing you could do to stop. If it went well, it was sort of like mutual cooperation, and everyone got a good feeling out of it, including the consumers being interviewed.

Isis: Well I think um, when - and I talked about this before - when an interview goes pear-shaped, that then, and not knowing what to do at the time, there was a feeling of powerlessness. I'm thinking: what do I do? Do I keep going on, do I soldier on? So that for me was an issue of power. So I was trying to find out what's my role here, how do I be more in control of the situation? And I didn't know at the time. So this has taught me what to do if I'm ever in that situation ever again.

Gillian: Ok, so there's been an experience of feeling really out of control and powerless, but you feel you've learnt from that.

Isis: I didn't feel I was, myself, out of control, but just the situation.

Gillian: Yep, the situation.



Isis: I wasn't prepared for it, but now I am. So this project has really helped me as far as any interview or communication with other people, I know what to do next time. I'm more aware now.

As the quote from Mandrake that opened this description of the theme power and powerlessness indicates, for some CRs, the learning experiences that were built in to their employment were also times where they felt a sense of powerlessness:

Ruth: When I haven't understood things I've felt powerless.

Gillian: Yeah

Ruth: That's just because I didn't understand myself, but I feel "what's wrong?" "why" you know, am I less than others? or "aren't I concentrating?" "can't I remember?"

Gillian: Yep

Ruth: I ask myself those questions, [laughs] rather than just sit still and relax, and take in what I can.

Susan: When all that evaluation stuff dropped into place, I had that feeling of powerlessness as I was being swamped with it, and then it suddenly just dropped into place, and I could sort of finally analyse it and knew what all the stuff was for, if you know what I mean.

Gillian: Mmm

Susan: And it dropped into place and I had this feeling of power then because I could move elements around and actually make deductions and stuff, instead of just being swamped by incoming material.

For this participant, learning experiences in her work as a CR began with a sense of powerlessness, but as she became able to master each topic, she felt a sense of growing power.

Another CR spoke about her experiences of planning and preparing for a conference presentation, however making the decision that she would not present, due to mental health concerns:

Ann: Well, the only time I felt powerless was at the conference when I couldn't present the paper.

Gillian: Yep

Ann: That for me, hurt. You know, I had no control - well I had kind of control, but I had no control. And that was probably the worst part of it, not being able to do it, and having someone else read the paper

Gillian: Yep

Ann: Was really, really hard. Not that she did it wrong, it was just that I didn't do it.

The experience of not being able to fulfill her own expectations for herself, and contribute in the way she desired at the time, created a feeling powerlessness for Ann.

A sense of collective power felt through being part of the team was raised by one CR, who spoke about feeling a sense of power building out of interactions with the team:

Ruth: Yes, that's where I felt power. Because where Algernon can contribute, you know, and says things, and it's 'oh yeah, that's right' and I agree with him, and Susan, and Mandrake, and you know, it will just trigger it off, and I feel a sense of

power then, and yet it's other people that are saying the things, but I'm agreeing with them

Gillian: Mmm

Ruth: not just to be agreeable, but because I think it's right. But I just didn't think of it. [laughs].

Gillian: Yep. So there's a feeling of power as we work as a team for you, and as that energy increases and people say things that you agree with?

Ruth: Oh yeah, I feel powerful when we're all together.

During the discussion, the team explored the question of whether the traditional balances of power had been changed, or challenged by interactions within the project team. This was a question raised during the discussion by Algernon. Their consideration of this explored the complexities of the research, and team process, as well as the relationship between the two poles of this dichotomy:

Susan: Well, at the moment we're sort of dependant on the questions being fired at us, but on the other hand, we have the power and the resources to come up with the answers - especially amongst the group. So there's a combination of empowerment and powerlessness flagged together.

Gillian: Ok

Walter: I think as far as the culture that's been promoted during this project, is to give consumers power, or to give them a place so they can be listened to, or whatever. And I think in terms of what happened at the conference was quite - it was, consumers did express, we did say what we mean, we did say what our own experiences were. There was an audience that listened. So there is a – a real case

of consumers being listened to, in our case. So in terms of the power imbalance being addressed, this is a concrete example of that happening. You know, there were consumers' voices speaking out loud, there was an audience, and people were listening...And beyond that the papers will be published so there will continue to be an audience for that work.

Gillian: And one of the papers was about empowerment specifically, in relation to the project, San?

San: Yeah. ...I was thinking that um, we got power by getting paid. If it was just a volunteer job, I don't think the same amount of effort or the same values would be held upstanding. Because by getting paid you're getting power, like in the pay.

Gillian: Yep

Ruth: What I was going to say is that, where I'm at now, me personally, is that I understand you a lot better, and I believe you understand, when I say me I'm talking about us generally... I still see us as consumers and human beings, and you as academics and human beings. But I understand you a lot better now, and I hope you understand us better too.

Gillian: Yep

Ruth: So there's a powerful thing in understanding. It's not that one's better than the other, but when you can come together like that, and understand each other, then you can still be who you are. No-one's really changed, but we understand each other. And you don't have to feel like "oh, I've got to change to meet someone else's expectations". I don't have to speak like them I can just be me, you know. You can be you, and I can be me. And that's empowering.

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*Consumer Involvement versus Lack of Consumer Involvement*

The participants' discussion held two foci regarding involvement: their own, and that of the consumers who took part in interviews and focus groups.

Nic: we were listened to as consumers ... I thought that was good. We were highly valued for our point of view.

San: The consumers who we interviewed all expressed encouragement towards the project, saying it made them feel, to share information, to be a valuable part of something that was important. Otherwise they had nothing.

CRs clearly felt strongly about the importance of involvement, in validating and recognising them as important individuals:

Ruth: Being a consumer too, doesn't make you any less of a human being, you're actually very strong and courageous [laughs]. So being used, or being able to be part of this project, and um, doing this type of work proves that you're not any less. To be able to cope with things that you don't understand, like Walter and I were saying, but still being able to continue on, and being able to contribute, whether it's this much or this much

Gillian: Yep

Ruth: Is important ...as a person, to be recognised.

Other CRs discussed how involvement in the project has broadened their ability to be involved, or changed their involvement in other areas of the mental health field:

Mandrake: I see it um, there are other areas where I'm involved with consumers, and I see that the project has enhanced that aspect of my life.

Gillian: OK. In what way?

Mandrake: Oh, probably because I've devoted a little bit more time and attention to the issues that come up

Gillian: Yeah

Mandrake: ...my awareness has been raised, my consciousness.

One participant spoke about the personal impact of her own involvement in the project, reflecting on what it meant to her to have an opportunity to interact in this new way with other consumers of mental health services:

Susan: Hearing other's being open and honest about their situation has really been an inspiration for me to be able to open up and talk too.

Gillian: Ok

Susan: It sort of becomes socially acceptable, and then I feel braver.

During the conversation about this theme, San also reflected on involvement in the project compared with other options for involvement he sees as available for consumers, and discussed how important he felt the opportunity to be involved in the research had been.

### *Optimal and Appropriate versus Inadequate and Inappropriate Medication Experiences*

Participants agreed unanimously that medication played an important role for them in their experiences working as CRs. For most, this was an underlying principle: if they didn't take their medication, they felt they would not have been capable of the demands of working.

Susan: In my case it's the single most important factor in my recovery I think, because when I get ill it's just like a chemical phenomenon, I may as well be eating poisonous mushrooms or something for the way it happens to me.

Gillian: Yep

Susan: I'm just overwhelmed by the foreign chemicals it seems, and ...

Gillian: So Susan, when you say it's probably the single most important factor in your recovery, how does that relate to the project and the role that you play?

Susan: well...it's meant that I've been well in order to perform for the project.

When I'm not well, you wouldn't get me to sit down in a room five minutes, and I wouldn't talk on a rational level at all. You know I might start out saying something and then off with the fairies. There's no way I could even have participated when I'm ill.

Others agreed:

Ann: I think it's a major issue. During this project I've ended up in hospital twice for a month at a time because of the medication they've reduced. And the thing is, you have no control - they have control over the medication you have, but you have no control over what it does to your body.

Gillian: Yep

Ann: So you end up in hospital, and that's really hard. Even though you take it and you do exactly what they say, and you reduce it exactly when they say, and you end up in hospital.

Gillian: Yeah

Ann: It's the opposite...The impact is there um, on the research itself, because um, one of the reasons I couldn't present. You have so much thought blocking and you're so thought disordered, and you can't think to do anything, and it's really hard when you're trying to - when you're a consumer researcher trying to

do a research project, and you don't have the mental capacity because of the medication being altered.

It seems, from participants' conversations, that some of them also perceive the project as having played a role in their medication experiences. One participant reported he had reduced his medication over the course of the project, and another stated he has found his involvement with the project has become a talking point with his doctor: they now use this as a gauge of his well-being. Another participant, on this theme, highlighted how involvement in the project also creates a new and different life stress, or the possibility of stress, and that this is also something each CR was dealing with, which he sees as relevant to the issue of medication:

Algernon: well, you just take your tablet and hopefully it's helping keeping you well.

Ruth: that's right

Algernon: And it's just whether or not the extra stress of involvement with this project has affected your levels of medication, or how well it works.

Discussion around the theme of medication led CRs to consider the project's impact more broadly than medication also, suggesting involvement in the project has effects on their experiences of psychological distress that medication does not:

Mandrake: I think the project- there are some sort of negative symptoms from the illness, that I think the project has helped alleviate, like motivation and

Ruth: mmm

Susan: Yeah, medication doesn't really effect motivation or anything like that

Mandrake: yeah. So I think the project's been really valuable from that aspect.



Ruth: mmmm

Gillian: What are other people's thoughts about that idea?

Ruth: oh definitely

Susan: Definitely

Walter: Yeah, it's really important, because if you've got like an ongoing project to be involved with, it really changes your attitude to a lot of things.

Susan: Yeah. It changes your whole attitude to everyday life

Walter: yeah, and other things as well

Susan: Instead of being stir-crazy staying at home and you want to get out, it's actually a nice place to be at home, because it's a change.

Walter: See, even if it's only one day a week it gives you a focus for the week, you know that on Monday something's going to happen that you have to get out of bed for.

Ruth: mmm. That's right.

Mandrake: Yeah, it's a new facet of your life in a sense that it gives you some sort of meaning and purpose, and a pill doesn't give you that.

Ruth: that's right, yeah

Isis: The pill reminds you that you're ill

Ruth: Yeah [laughs]

Isis: Whereas when you come here you don't feel ill, and you're actually contributing and you've got a purpose.

This discussion raised similar issues as those described when discussing the theme of acceptance versus stigma. It appears that for participants, the sense of purpose and focus created by working on the research has implications broadly within their lives.

### *High versus Low Service Quality System*

CRs described positive system issues as including the support they received from the project team in a range of areas. The sense of a safe and supportive work environment was raised by Isis, who described the importance for her that interviews were arranged in venues where there were others present who could support her. Ruth talked of the support she received during periods when the work tasks were personally challenging. Ann stressed the importance for her, of the support and encouragement from the Consumer Representatives on the Management Committee. Walter saw the provision of food, which the team shared during team meetings as an important systemic support. Others discussed the importance, and usefulness, for them of their work transport arrangements facilitated by the Project Officer and PhD student. CRs also agreed that the remuneration they received was a positive system issue.

Another component of the system they worked in raised by participants was the administrative support offered to them in completing their time sheets correctly, and providing them with cut-off dates for submission to the university.

One participant spoke about the variance in support she felt from the academic members of the project team. She described this being one of the more negative system issues for her, describing what she felt was a “them” and “us” barrier:

Ann: We haven’t seen the team above basically - to really have that feedback from them.... And I think that’s a real flaw in the project, is that lack of um, you

know, communication with the team above. Sometimes you'd [ie. Gillian] come back and say. But we really haven't seen them, or been able to communicate with them. And I think that's put a bit of a barrier between 'us' and the academics.

Others in the team agreed that they had rarely seen the more senior academic researchers during the duration of the project. When I asked Ann what difference seeing more of them would have made for her, she replied:

Well I think it would have probably made us feel we were doing better. We get the confidence from you guys, and that's fine, that's really good and we appreciate that. But really they're the controlling body of this whole research and we haven't seen them, and we really don't know what's happening at the end because we don't see them now, you know. I think that's a problem.

CRs also raised the concept of having to fit within a new and different system:

Mandrake: Well I sort of addressed some of that in my paper about the power of the institution, the university, and its hierarchy and its status in the community, as opposed to ours – consumers - and I think that's significant.

Gillian: Yeah, and what sort of role did that play in your experience?

Mandrake: Um, it's sort of been a learning process. To become - we've been assimilated.

Gillian: Mmm

Mandrake: do you know what I mean? To a certain extent, we've still got our own identities, but you know, we're university employees; so um, it's a complex issue, I haven't really worked it all through.

Gillian: So are there positives and negatives? ...when you're talking about that assimilation stuff and that you are employees of the university, can you tell me more about it?

Nic: Well, that's a positive thing, I think,

Gillian: So in what way, Nic?

Nic: ah, a status thing, I suppose. We're employed by the university.

San: I enjoy just coming here, compared to a place like [work skills rehabilitation centre].

### *Responsive or Unresponsive to Consumers*

Participants explicitly linked their views about this theme, and its importance in their experiences as Consumer Researchers back to their discussion about system issues, and stated that they found the project to be very responsive. They revisited examples such as the assistance in filling in time-sheets correctly, when necessary, and assistance with arranging transport to work.

Algernon; I think you've tried to develop our role as consumer researchers, so providing the research skills training at the Library, providing PowerPoint training,

Ruth: mmm, all that

Algernon: providing presentation skills workshops. So I think you've done everything you can for us, to provide an environment where we can develop

Gillian: Mhm

Algernon: I guess, to be empowered, those sorts of issues. So I think we couldn't have asked for a more healthy environment for us to develop ourselves.

San: I think you've enhanced our um, situations, by giving us extra options away from medication and the medical side of our illnesses, sort of focusing on re-training, and getting us skills and ...

Ann: Self-worth. It's been good.

Gillian: So have there been times when the project hasn't been as responsive to people's needs when they thought it should?

Mandrake: as far as a workplace goes, I think it's been more than adequate. I think there's been a level of compassion and empathy that's just non-existent in other jobs, you know, there's more understanding. So in that way, it's been more responsive.

CRs also stated that they had felt personal interest and empathy, not just professional support, and that this had been important for them:

#### *Satisfying versus Dissatisfying Relationships with Staff*

Generally, participants in the focus group suggested that relationships with the staff, or academic members of the Project Team were important to them in their experiences of becoming researchers.

Mandrake: Well I think the attitudes have been sort of healthy attitudes, in this whole experience, from staff. Um, I haven't experienced any discrimination, or patronising attitudes, or um, it's been very professional, and it's been done well, and it's what you expect. Plus it's been supportive as well, so overall it's been good. I can't think of any significant issues in my relationships with staff, where I've thought "oh, gee that's surprising." I can't think of anything significant.

Ruth described her perception of the relationships as beginning with particular views about the academic members of the team, but over the course of the project, finding her perceptions were not validated:

Ruth: From the beginning, when we were first talking about it, I thought, well, gee you're academics and you speak a certain way, and you've got this high level of education and I don't. But then as we all started to form our words so we could all understand each other, and you sort of toned down a bit, I remember you saying "it's all academic jargon" or something like that. And that made me feel comfortable. Because I don't want to have to put on and be something I'm not. I'm comfortable with who I am, and I don't want to start to talk in a different way, or speak in a different way just to suit somebody else. If I choose to that's different, but you know, I thought the way we started to interact and develop a relationship in our work was good, I feel very comfortable with that.

She described feeling comfortable, able to be "herself" with the other team members – academics included.

Overall, participants described their relationships with staff in the team in generally positive terms, however Ann's point earlier relating to not seeing enough of senior academic team members indicates that some participants felt limited opportunities to develop genuine, collaborative relationships with some of the academic members.

### *Supportive or Unsupportive of Relationships with Community, Family and Other Consumers*

This theme also appeared to participants to be relevant in their experiences of becoming researchers. Many participants had already related some of their views about

how the project facilitated, and at times hindered, their relationships outside of the project team, particularly when discussing the theme of acceptance versus stigma. Several participants spoke about how their employment as CRs had enhanced their personal relationships with friends and family.

San spoke about the different relationships in his life, and the different role the project plays in those:

San: It's sort of like you're on a level playing field with other people that have got a career. And the important fact about that is that we're getting paid, and you can sort of talk at the same level.

Gillian: Mmm

San: Whereas, if I talk about it at [rehabilitation centre] where I'm volunteering, you can't talk about that because they can't understand it, because they haven't had any experience of that in their lives.

In terms of the aspect of isolation, which was a component of the theme as described in Chapter 8, participants said:

Ruth: Well our involvement breaks that isolation, doesn't it. Because you can't be isolated and be here can you? [laughs]. Whereas - not personally myself, I know I would be doing something else today, but there might be someone that wouldn't and feel isolated. But you can't be isolated and here at the same time.

Gillian: Yep

San: if we had more time on the project, like working extra days and things too, that would change the isolation.

Gillian: Yep

San: because, you'd only be isolated if you weren't doing anything.

Ann: The only time I felt isolated I think, was when I wasn't well and didn't have much contact with the team for a few months. And then I felt very isolated, and quite nervous about coming back into it and having the contact again. But once that contact's made, you feel pretty good.

However, for at least one CR, some of her experiences working created an increased sense of isolation during some points in the process of work:

Ruth: Well, now I'm actually thinking about it again, when I was at home and going the analysis work, I felt isolated, because I was being affected by everyone's experiences, and I felt very isolated doing that work, as you know, because we talked about it before. Whereas I would probably have been better off being in a group - well I couldn't have been in a group, but with other people. So that was a feeling of isolation.

Gillian: Yep.

Ruth: due to the project. Just an area that needs to be addressed in the future.

In terms of a sense of community, CRs generally agreed that working on the project had created a new community for them, and a new sense of unity and belonging:

Mandrake: well, I think the fact that we're working together as a group, it's sort of a small community in its own sense. So, along with that you know, is the belongingness, and a sense of security being in the group. I think it's a new sense of community

Nic: mmm. I'd agree with that.



Ruth: Yeah, whereas I never really knew Susan very well until we became part of this group, and now I feel very close to her at times, when we're chatting, -

Susan: Yeah

Ruth: And about personal things, we don't always talk about the project

Gillian: Mmm

Ruth: Whereas before, I might have felt isolated from Susan. I mean, that's another form of isolation, isolating from individuals. So, because of the project and team work, I don't feel that isolation with anyone here, that I might have before.

Algernon commented, however, that particularly during the first stages of the project, he felt there were large gaps of time between each session when the team met. He felt these hindered a sense of community early in the project. This discussion led to reflection on a broader linking with community, and participants reflected different views about this. For Walter, his connection with the university became significant:

Walter: it's also - the more the work, the more you sort of tend to see the relationships that exist between other groups that work within the mental health community.

Ruth: Yeah

Walter: Like, there's the learning about this department here, and the learning about academics, and their relationship, and we understand about that and their relationship with consumers. But there are also the doctors and psychiatrists as well, so it's interesting to see that those other relationships exist within the mental health community.

Ruth described a sense of connection and belonging with others at a conference she attended during the course of her employment as a CR. She spoke about feeling a sense of commonality with other people attending and presenting at the conference, because of her work as a researcher:

Ruth: Well at the conference, even though I never spoke to a lot of people, I felt a relationship with certain people because of my involvement in the project. When I'd sit and listen to other people talk,

Gillian: Mhm

Ruth: With different papers and that, even though I didn't do that work and I don't really understand it all, I could relate to that and understand them because we've been working in a team, and getting information, data, and working out, not formulas, but putting ideas forwards, and working out, getting plans and that. So when people were talking about their projects and things, I felt a sort of link with them, and a sort of relationship with them, even though I didn't know them....Through doing, being part of this project, I was feeling, yeah, a link with these people I don't know, and I may never see again. It was quite good, it was a good feeling. I felt part of it, not like an outsider.

### *All of Me versus Me as an Illness*

This theme seemed to be of significant underlying importance to the participants in their roles, as one aspect of their broader lives, and conception of self. For example, Mandrake said:

I think that 'all of me' concept is very important, because I see the fact that I'm a person first, and I see the illness is just part of me. I don't see myself as a consumer,

Gillian: Yep

Mandrake: I don't look at myself as a consumer. Um, it's just a part of me, but - and so I don't tend to focus on it. And I think that's important.

Gillian: Yep

Mandrake: And I think there are a lot of areas there that have all applied. Um, it's given me an opportunity to achieve, you know. Doing the focus group, that was the first time I'd ever done a focus group

Gillian: Yep

Mandrake: And being trained in how to run a focus group that gave me confidence about how to run it. And about how to have a [semi] structured interview, that it's a bit different from having a conversation, like there are things you want to achieve out of that communication. So that was all fairly valuable, so I felt I'd achieved there. Um, exploring issues for self, well that's an ongoing thing. So in a sense, the fact that we've been given some research skills has helped that process.

Ruth agreed, and highlighted the comment Mandrake started with, that he doesn't see himself firstly as a "consumer":

I don't see myself as a consumer until I go and sit there and talk to a doctor or get a prescription or take a tablet or something like that. I'm a whole person, and

being part of the project, I'm a person sitting here willing to contribute and help.

So that's how it is for me.

Gillian: Mmm

Ruth: As a whole person, in this project. I don't see myself AS a consumer, even though I do use the services.

Gillian: Mmm

Ruth: And that, its' just at certain times when I take a tablet or something like that, you know what you're taking that for... You are a person, you're not an illness.

Relationships that were forged between the team were raised as another aspect of the theme relevant to CRs in their experiences working on the project. CRs saw the skills they have learnt as researchers as important life skills, also relating to a broader sense of self than purely as people with mental illnesses:

Ann: I think as Mandrake said, I think the skills that we have learned are really lifelong, things that we'll always have. And be able to understand, I think it's got to benefit all of us. You mightn't see it, it might just be in talking to somebody, not interviewing them, but having those communication skills we didn't have before, just in talking to other people. They can only enhance any other relationships we have in the future.

Ruth: It's taught us too, to listen more. We all want to jump in you know, and have our say. But when you're interviewing someone, or in a focus group like this or facilitating it, you're listening to other people, and it's teaching you to be more attentive and to listen.

Walter: I think that's true too, that the process of what we learn on the project does really inform your attitude about working with people in the area of mental health with consumers.

Ruth: yeah

Walter: It does, you learn things about your own attitudes and your own preconceptions

Ruth: Your values

Walter: your own values and your own ways of seeing things. You change when you have to put them into place, well they change anyway.

Ruth: And interacting with staff too, down at the rehab centre, I've noticed after interacting with you here - the whole team, but you're the one I see most [laughs], anyway when I talk to staff at the rehab centre, I feel different you know? I start to feel more like I'm one of the staff. And I've been there for years and years helping out, you know, and I've sort of felt like they were a bit up here a I was down there ...the thing is I don't feel - I feel more balanced with them because of the work I've been doing here.

## Results from Analysis of Interview Responses: Exploring Personal Journeys of Becoming a Researcher

### *Having a Job versus Not*

This theme from the interviews related to general features of employed. The importance of being paid, and having an income; the sense of fulfillment and meaning a job can create; and along with this the understanding that work provides a way to contribute was discussed. For example, Ruth said:

Um, being paid well - most of my work I don't get paid for, and I still do it, it doesn't stop me. But actually being paid [laughs] it's been very good.

Gillian: mmm. So what does it mean for you to be paid for that work?

Ruth: Oh, it ah ... I don't know. When you get paid for something, you feel more important don't you? Being a volunteer is, is very difficult, because you only get a thank you. And a thank you is good, but I don't know, you get a thank you and no one ever mentions you again.

Gillian: Mmm

Ruth: But I don't know, when you're getting paid for something, you seem to feel more valuable.

Walter also spoke about the importance, for him, of having a job:

It's been good to have some work to do. That's the other thing too; I've got to be involved in something, which is good.

Gillian: mhm, so what difference has that made for you?

Walter: well it gives you a purpose, there is a purpose to the project and there's a purpose to being involved.

Another important feature of being in work that some of the participants discussed is the focus outside of themselves – their own routine and life - that work creates, providing stimulation and a new area of thought:

Susan: Well, just the getting up and getting out for the day is um, you're out the whole day, and especially when you're a bit house-bound because you've been unemployed for too long, just the getting out of the house for the whole day, and

all day long your head is somewhere else, and you don't even think about home and your problems at home

Gillian: Yep

Susan: You know, you're working on something else, and it's just so refreshing.

When you get back home you feel like you've had a holiday from your life.

San also conveyed this idea:

I just sort of think it's good to do this job, apart from not doing it. Because it gives you the option to deal with something outside of yourself and not be so concerned with yourself all of the time.

Participants also described that having a job was a way for them to seek status within the community:

San: It's given me a title, and it's sort of like, just having a job position. Instead of just being an ordinary consumer, I've got something else to say I'm a bit better than that. It's like a progression.

### *The Positives and Negatives of the Work Environment*

Participants interview responses also related more specifically to features of the CEO-MHS project. While the previous theme focuses on issues that relate to having any meaningful job, this theme is more specifically related to features of this particular work situation.

The theme incorporates a range of positive features of the project that many of the participants included as important in their experiences of becoming researchers. For example, they spoke about the importance of working in an environment where their experiences with mental health services were openly acknowledged. Some participants

reflected on their experiences in their position as CRs, compared to applying for other jobs, and how acknowledgement of their experiences as a consumer made the application process much easier than other job applications and interviews:

Isis: It wasn't as intimidating as other job interviews I've been to in the past, where they're not aware that you're mentally ill, or haven't got any issue like that in your life. So that was really very um, a relief, a big relief. I walked out thinking I feel really good after that. That was really good!

Mandrake also reflected on the interview process when CRs were recruited to the research team, and how acknowledgement of his experiences as a consumer made a difference:

They sort of asked me about my education experiences and that, and ah, also my experiences as a consumer, and um, yeah. I didn't - like some interviews in other jobs you go into, I'm really conscious of the fact that I've got a mental health history, and I don't know whether to divulge that or not, so I feel really uncomfortable,

Gillian: yeah

Mandrake: and plus I've got gaps in my employment history because of mental illness, and you don't know what to say, about what you were doing in those periods. But with this job, with this interview, I could be quite honest, so there wasn't a problem there.

At the same time, some participants also mentioned that while there was acknowledgement, a positive feature of the project was that staff didn't ask for details of their experiences. For example, Ann said:



They were good, they didn't ask directly you're experience - um, what was actually wrong with you ...which I found good. It wasn't - I didn't feel my personal space was actually impeded at the interview, and that made me feel more confident in going on.

The research itself, and the overall aims and design of the project, were mentioned too, as something participants felt to be worthwhile, and something of which they wanted to be part. For example Ruth said: "when it really sank in what we were doing, or trying to do, I felt proud to be part of it" and Martin reflected: "I just thought the idea of this research was good, even though I didn't really know that much behind it at the time, but I thought it sounded good and that I'd like to be involved in it"

Other features of the project raised by the CRs were the supportive work environment and atmosphere, and the creation of a space where they felt valued and heard. For example, Martin said:

I thought, I'm doing a job where people are asking me what I think about things, and what I think someone is saying, and I thought that was a valuable thing, people are asking of me something that is quite valuable.

San also spoke about feeling valued and respected as a member of the team:

I feel privileged to be doing that sort of work because it's something I haven't experienced before, that sort of academic level. I appreciate you sharing that with me, that sort of knowledge and skills.

Mandrake also reflected on the supportive atmosphere he experienced, working as a CR:

Mandrake: I felt so much at ease in this job, because there was no...Like if you stuffed up, I'm not saying there's an excuse, but it just seemed that the atmosphere was so supportive that it wasn't a big issue..

Gillian: Yeah

Mandrake: and it just helped me to free my thought processes

Martin spoke about the flexibility of the work, and the choice he felt available to decide which tasks he worked on:

Martin: one thing I want to say is that there was a choice for me to do that [analysis of data], it's not like that was the only available thing to do, because other people did very different things to me,

Gillian: Yep

Martin: and I thought this is really good that I can choose to do like the actual interview analysis and the focus group analysis because that's where I felt I could provide the greatest input.

Gillian: Yep, so what did that choice mean for you?

Martin: Oh I just thought: this is really good because I've just sort of picked up this causal job which has now given me this quite important role, which is a real bonus.

The theme also incorporates discussions of some features that are specific to the project but were seen as more negative. For some, the use of the label 'Consumer Researcher' provided a challenge and conflicting feelings:

Mandrake: I sort of dislike the ...fact that we're labeled as consumers as opposed to just using our names or whatever. I know it's valuable in terms of providing

information, but you can't always guarantee the person who receives that information is going to - how they'll react or behave. Unless you tell people - I don't know, I don't know. It's just -

Gillian: Mmm

Mandrake: I'm probably sensitive to the fact that consumers have got - there's a lot of stigma around and it depends on the person, but I've heard some really bad examples of stigma - so I don't know whether in the project the fact that well, that's the only reason we got employed was because we're consumers. I know it's early ground yet, and I see that as an objective of the project, that it's establishing that we have something to offer, and I would hope the project would see that um, we don't only have something to offer as consumers, we have something to offer as people.

### *Broadening Personal Horizons versus a Narrowing World*

This theme relates to the concept, conveyed by participants, that their experiences as CRs were personally enriching, and broadening. The theme was evident in each of their stories, and includes a number of sub-themes. Each sub-theme elaborates the core idea of broadening personal horizons. These sub-themes include: self: personal growth; the importance of relationships versus isolation; learning; new experiences, new perspectives; and the unknown.

#### *1. Self: personal growth.*

The sub theme of self: personal growth relates to various threads in the discussions participants had. They highlighted the sense of personal growth in becoming

researchers, noting growing confidence and self-esteem becoming established during the project:

Isis: I feel very accomplished, I feel very confident. I feel talking to people, not just about mental health issues, I feel like I could conduct any interview perhaps. I should be able to use all those concepts, like the actual ...

Gillian: The skills?

Isis: The skills, yes, of doing it. I've practiced and I know I can do them, and it's not so hard once you know how.

Gillian: Mmm

Isis: So that feeling of confidence, independence and um, being able to do it well.

There's a word and I can't think of it - being self-sufficient, yeah. Self esteem boost too.

These sentiments were shared by all of the participants, describing themselves as "successful"; and talking about a growing sense of self-esteem or self-worth and growing confidence they developed as they worked as researchers. Many of the participants when asked to describe how someone might have seen themselves when first applying for the position used terms like inferior, and inadequate. A clear transition towards seeing themselves as more valuable and competent was evident in all participants' stories.

Martin said:

all the time being involved in this my self image is improving...I thought, I'm doing a job where people are asking me what I think about things, and what I think someone is saying, and I thought that was a valuable thing: people are asking of me something that is quite valuable. And it's sort of the way I work

with things anyway, is sort of like I put, because I'm like into artistic things: I put my feelings and interpretations of things into what I produce, and that's the way I did it and it still worked that way. Yeah so that was good.

Some participants also reflected on how they found themselves exceeding their own expectations through their work as researchers in the project. For example, Isis stated: "I've done things that I didn't think I could do before"

Participants talked about having their beliefs and ways of understanding things challenged, finding new approaches to understanding parts of the world through their experiences as researchers. For example, Mandrake discussed how working with the team lead him to reconsider some of his views:

Mandrake: I didn't realise that it was going to be so people centered; well I suppose I should have guessed that. But a lot of my reflections have been in a personal sense. What was happening for me, how was I coping? And all of a sudden I've been exposed to other people's experiences as well, in a semi-formal situation. Whereas before I might have been exposed to other people's experiences in a recreational sort of atmosphere,

Gillian: yeah

Mandrake: so there was sort of a bit of an expectation in this semi-formal [environment] - to have some answers. Well, to be able to recognise it. So there was this sense of validity that you had to give to those experiences that you mightn't have done in a recreational setting. You know, it might have just been a story and you'd have laughed; that sort of carry on. But here it had a bit more meaning and a bit more significance. So I guess the option there for me was: here

is something where I can take this experience on board, and I can learn from this.

Because I've been involved in a recreational setting just sort of poking fun at psychotic symptoms, you know, just sort of laughing about things that have happened to me, and not really thinking seriously about them - but here they seem to carry a bit more weight.

Gillian: Mmm

Mandrake: So the option there for me was to consider my experiences a little bit more seriously than I had done in the past.

Participants also reflected on how they had been challenged at a personal level during the course of becoming researchers, highlighting times when they questioned themselves and their abilities, or felt like they had failed. A comment Susan made in one of her interviews sums up this aspect of self: personal growth:

It's been more challenging than I thought it would, because I thought we'd be basically told how to do a quick interview and that's all. I didn't realise there was going to be so much scope for me to learn and develop from it.

Nic reflected on his concerns which related closely to his view of himself, and the process of this being challenged, during the course of his experience as a CR:

Nic: Ah, getting my hands dirty concerned me. That's why I avoided getting involved, and didn't volunteer to do a focus group.

Gillian: Mhm

Nic: Um, if I had my time over again I would do that

Gillian: So when you say getting your hands dirty, what do you mean?

Nic: I guess I feared getting out of my depth. I tend to think, I have this attitude which is that, that if I try something and it doesn't work, I'm quite self-critical. And um, I've got to realise, if things don't work, it's not the end of the world.

Gillian: Mhm.

Nic: Because, I've just got to see success as a mixture, even if something's a failure, in a sense it's a success because you've attempted something. Things started to change when I did actually - started to do some of the interviews

Gillian: Mhm

Nic: And it wasn't so bad, I survived them. [laughs]

Gillian: Ok, yep

Nic: Um...

Gillian: so it wasn't until you started to actually do the interviews that you felt the idea that you would fail was starting to be challenged?

Nic: Yes

Gillian: Yep

Nic: And maybe - I can't remember with the interviews, but I thought oh well, why not - but um, maybe it changed before then because I decided to do the interviews.

Gillian: mmm. Yep.

Nic: I thought - it's getting late and I might miss out

Gillian: mm. So there was a sense that if you didn't hurry up you'd miss the opportunity completely

Nic: Mmm

Gillian: to actually get involved?

Nic: Mmm

Gillian: What would have happened if you had let the whole project go by and you hadn't got your hands dirty?

Nic: Well, I would have regretted it, not doing something.

Later in the interview we touched back on this:

Gillian: So, how have things gone compared to how you thought they would?

Nic: Well, I've been a success in two ways.

Gillian: mmm

Nic: The second way in which I've had something to contribute towards the evaluation ...what do you call it?

Gillian: yep, the Framework

Nic: The Framework part of it.

Gillian: so, you've succeeded in having something to contribute at that stage. You said there were two ways, what's the second one?

Nic: And the lesser way, the interviews.

Nic's perception of himself changed during, and it seems, in part due to his time and experience as a researcher, from focusing on being a failure, to seeing himself as a success. He commented later in the interview: "maybe I've grown a bit as I've got involved." Susan also reflected specifically on an interview experience she had felt challenged by, during which she found herself uncertain of how to respond to a participant's story:



And it was a bit shocking, I didn't really know what to say to her to sort of defuse the situation, but it wasn't really a situation you could defuse, it was such a bad thing she was talking about, and just me being shocked and sympathising was probably the best thing I could do.... I felt a little anxious about if I'd done it right, as in whether I'd done the best thing to sort of um, ease her trauma, or you know, if I'd been human enough about it. But at the same time I felt that was all I could do, was register shock, because that was what was happening to me, you know. What she told me was so shocking and I didn't get any further than being shocked.

Ruth reflected on her feelings when she chose to work on analysis of the interview material, and found this work too stressful at that time:

Ruth: It wasn't like I was just doing a couple of interviews; I had to read the lot.

Gillian: mmm

Ruth: and take notes, you know, I've got to remember and write it down, and so, it just stayed inside of me. And I'd try to read another one and I've still got the others inside my head and you know, we're trying - we're picking out points that people make. And oh, all these people that had all of these side-effects, and had to cope with all these drugs. And I've attended so many meetings where they take, you know, record of who died and how they died, and all this sort of thing. And some of them were talking about suicide, and oh gosh, it was just an overload...

I thought to myself "I should have done the interviews and not done the analysis"

Gillian: mmm. So there was a sense of regret there for you as well, with that?

Ruth: yeah, and a feeling of failure, all sorts of things, and I don't like that, because I've been through a lot in my life and usually I put one hundred percent into anything that I want to do. And for whatever reason, I couldn't, and I felt a failure.

Participants more often related these challenges back to an overall sense of growth, feeling they had learnt something about themselves sometimes despite the discomfort the challenging times had brought. They, however, also sought personal challenges during their work as researchers, as Isis relayed, describing her choice to travel to other parts of the state, a choice she described as surprising herself:

I think it was exciting, and this is such a great way to actually put - really test myself - and actually get to travel and really be part of something exciting. I mean, I know interviewing Illawarra, that was like exciting to start off with, but this is really going out and doing fieldwork: this is really exciting. I'm really looking forward to this. When we got to Katoomba, like the actual traveling, that was probably not the most pleasant, because I don't travel well. But actually getting there, that was like "Wow, we're here, we're actually doing it" this is really good. Even if we had interruptions or people starting up cars outside the window, or a cat walk in, or get caught with the sprinklers. All of that was like a big adventure really.

Many of the participants also, however, relayed moments where they felt challenges were strong enough that they questioned seriously whether to continue working as researchers.

Some of the participants reflected on how becoming researchers related to their spiritual development:

Mandrake: and also it has something to do with - I don't know how to tie this in, but my belief system. I started to take a fresh look at my belief system. I started to think more - less, less about a corporate belief and more about a personal belief.

Gillian: Ok

Mandrake: I don't know whether you can do that - but I started to take into account more and more what my beliefs meant to me and what value it had in my life, and that carried over when we started talking about values and that, in life.

Gillian: mmm.

Mandrake: so that in a sense was significant.

Gillian: mm. so when you're comparing a corporate belief system to a personal belief system, can you explain that just a little bit more?

Mandrake: Yeah, what I mean by that is that ah, I belong to a church, and part of that religious observance involves being in a group, sort of group worship or whatever you call it. And I started to take a little bit more notice of individual - like my relationship with God, so to speak. I don't know how that ties in - but perhaps I was thinking more, thinking a little bit more.

Gillian: mhm

Mandrake: because that's one thing that the project has done, it's opened up new areas of critical thinking. Because I've been able to observe how you guys work, right, academics work

Gillian: yep

Mandrake: and um, and the depth to which you guys go to get information or to resolve problems, or whatever's happening.

Gillian: Mmm

Mandrake: but I've probably, I'm probably starting to think a little bit deeper.

## *2. The importance of relationships versus isolation.*

Relationships were a central concern in participants' interviews. Most of the components of the theme relate to relationships within the project team. For example, Ruth reflected:

we did all start to blend, when - at times we did come together very well, interact very well, and that was good. And sharing between each other, consumer to consumer, that was good.

Ruth: as we went along that barrier kind of went and it felt really good.

Gillian: mmm

Ruth: As we became a team.

Isis spoke about having the team around her during training, and the strong team feeling that had developed is clear:

that was a lot of fun doing it with other people, um, everybody else, making mistakes along the way: thinking I'm not the only idiot here [laughs]. Anyway, that was really good.

Mandrake highlighted the centrality of relationships for him, in his experience as a researcher:

Mandrake: it was very personal the whole experience, I think, because all the time, like, it was a meeting. We were relating to people, we were talking about ideas, we were talking about concepts, we were talking about principles, values and data, whatever. But it was all people orientated, now see, a lot of my work has

been orientated around physical, inanimate objects [laughs] and that relationships - relating to another person wasn't such a strong component of my work experience.

Gillian: Yep, yeah

Mandrake: So that was different. So I didn't have that expectation when I went into it - that was new. And I think that's where I've learnt a lot.

Later in our discussion, Mandrake elaborated on this point further:

But the fact that we went on this personal tangent was really valuable.

Gillian: mmm

Mandrake: because I found that, whereas I might have been a bit judgmental before, in my attitudes to people's behaviour, I found myself becoming less judgmental!

Gillian: Mmm, yeah

Mandrake: And if somebody had an opinion, I wasn't ready to sort of criticise them, or jump down their throat with "that's not right": I was thinking, hang on, they listen to you, you listen to them. So there were these aspects of working with people, in a relationship sense, that were, well confronting initially, but were growth, were a growth stage for me. And I started to think, well, that's something I haven't considered in the past. I think that's helped improve my relationships -

Gillian: Mmm

Mandrake: relationships outside.

The way in which the team interacted and developed was discussed by CRs, and the supportive, welcoming environment created by the team was highlighted. For example, Ann reflected on the team's interaction and development:

Ann: I think, the focus groups, we'd all kind of experienced them and we realised the practices before hand did work,

Gillian: yep

Ann: and that was on each other, and we could talk to each other.

Gillian: yep

Ann: And we could actually disagree with each other. And I think at about that time, just before the interviews, we came together. And I think the evaluation showed that we actually can work as a team

As well as this, however, the gaps between different parts of the team, CRs and management committee for example, were also highlighted. The project as an opportunity to meet new people and so expand their relationship networks was also discussed. Some participants spoke about experiencing a sense of validation from interactions with the team, or through their interviewing of other consumers. The importance of hearing other consumers' stories was highlighted. For example, San spoke about the connection he found when interviewing other consumers:

San: I felt pretty connected to the people that I was talking to.

Gillian: yeah

San: And if I saw them again, it'd sort of be like I'd have instant rapport with them.

Gillian: yep

San: That was good to me because I don't have that in the community. It was sort of like a new experience for me, different experience. It was sort of like it was giving me rapport and people I could relate to. People who go to [public mental health rehabilitation service] I don't talk about those things with. It's considered taboo.

Some aspects of the theme, however, also relate to beyond the team. For example, isolation was raised, at times as something the project has helped battle, but at other times something some participants experienced more strongly because of being part of the team. For example, some participants spoke about having to take time away from the project, and related feeling greater isolation, because they missed the team.

A further component of this theme is about challenging society's views of mental health consumers. Some participants spoke about this very personally, within their immediate relationships, and other's spoke more broadly, focusing on the status that working as a researcher brings.

### *3. Learning.*

Learning was a strong theme in the interviews, and linked to many positive and negative emotions, as well being interconnected to the other sub-themes described here. Mandrake, comparing focus group and interview training at the beginning of the project, to evaluation framework development at the end of the project said:

Mandrake: I could understand what we were doing there [at interview and focus group training], which was a bit opposed to how I felt through the evaluation process [training in evaluation theory and methods, and developing the CEO-

MHS Evaluation Framework], which was bewildering [laughs]. I couldn't get a handle on that at all,

Gillian: yep

Mandrake: I mean, even though it was explained to me, I brought it up as an issue, one of my personal issues my brain just refuses to recognise it long term.

[laughs]

Despite the struggle Mandrake describes here, he also spoke about the benefits he found, in doing the harder work of developing the Evaluation Framework:

Mandrake: It was interesting, I hadn't considered what a value was prior to that.

And I looked at values, I remember looking at values, and ah, yeah, I thought oh

yeah, this could be a guiding mechanism for making decisions in your own

life...just a lot of spin-offs from the project I think that you might carry on over

into ordinary daily life

Other participants also reflected on the sense of accomplishment they felt when they grasped the more difficult and challenging learning experiences.

Learning was clearly a formal component of the project, with a series of training sessions over the three years. For some participants, the process of learning, particularly the more formal sessions, was challenging, accompanied by feeling overwhelmed as they faced new and complex ideas to work with, as the discussion Mandrake had above indicates.

Participants, however, also spoke about the more informal learning that came with becoming a researcher: for example learning from difficult situations they had not expected; learning about working effectively as a team; as well as the learning about



themselves relayed in the sub-theme self: personal growth presented earlier. Many participants spoke about how the project was a place where they learnt about themselves. For some this occurred through facing some of the difficult situations; for others it was through interacting with the team:

Susan: I always thought I was intellectual, but socially not up to it, you know. So, to be able to keep up with all that was quite good.

Gillian: so to be able to keep up with all of that - is that in terms of with the team?

Susan: Yeah, with the team ... I get on well with the team.

Most CRs also spoke about the project as a source for learning new skills, and gathering information. This was important to them, because they saw the skills as having relevance and currency in a range of other possible work roles, as well as more general life roles.

#### *4. New experiences, new perspectives.*

Many CRs described the project as a situation where they encountered new experiences. Many of them described the type of work involved as new in itself, which opened up the opportunity for many new experiences. For example, Isis said, when asked to describe her experiences becoming a researcher: “it was something I hadn’t done before, and there were so many new possibilities and so many new experiences to have and to talk to people, and new things to learn.”

Participants also described the experience of becoming researchers as one in which they developed new ways of looking at many issues, including themselves, the mental health field, other consumers, universities, and research. Susan described clearly

one experience of finding a way to make sense of something new as she talked about working on the Evaluation Framework development:

it was as if I was doing a sum, or an equation - arithmetic or something. And I had no idea how to approach the problem and that was the overwhelming part...And then finally you had the process, you know, you've got the formula or something.

And you know then that  $c=2$ , ah! Well, if  $c=2$ , the whole sum means something. Part of this theme also is the "flow-on to the rest of life" many participants spoke about, which also relates to the sub-theme above. Ann, for example, spoke about how what she learned as a Consumer Researcher, through conducting interviews, could be related to her role as a mental health clinician:

I [started to] think, why haven't I been doing that in my role as a health professional, why don't I - you know - put an equal footing as a consumer and interview from that perspective, rather than from a more impersonal perspective. So I've learnt that...After I'd done the interviews [as a CR] and went back to work, I tried to do that. And that was a really different interviewing process I used, totally, from that before. And they were - the people - were far more responsive to that kind of approach. It was really rewarding, and I felt like saying 'listen here you world of mental health clinicians, do it this way, you'll be right'.

Participants spoke about seeing the acquisition of both new skills and new ways of looking at things, as useful to different contexts of their working and personal lives, as previously indicated in the sub-theme described above.

### 5. *The unknown.*

Many participants also reflected on how they had been unable to anticipate what was to come with the research, particularly at the beginning of the project. Nic, for example, described the first stages of the project as the “big unknown”, stating he had very few expectations of what would be involved. Often, this sense of the unknown, or unexpected, most powerful in the beginning stages, but apparent throughout the project, linked to feelings of uncertainty, and at times confusion for them. Walter described this sense for him:

Walter: I think it was quite difficult, because it was quite difficult to get a grasp on what the project was about, so it was challenging.

Gillian: mhm

Walter: challenging to try and get a grip on what is it we're going to be doing, to be able to see into the future almost -

Gillian: Yeah

Walter: based on the past. So it was challenging.

### *The Positive and Negative Emotional Experiences of Becoming a Researcher*

Throughout their stories of becoming researchers, all participants spoke at times about the emotions they experienced along the journey. A huge range of mixed emotional experiences and reactions, both positive and negative were discussed. Some of the most prominent negative emotions included: anxiety; stress; confusion; being overwhelmed; uncertainty; pressure; and being nervous. Ann described conducting a focus group, saying: “it was quite daunting and I think I was very nervous, because I didn't know these people and ah, I felt uncomfortable because I thought ‘oh, what am I doing here?’”

and Susan described her first feelings when starting the initial training: “at first I must admit I was very overwhelmed, when we started getting so much information” Often these more negative emotions were discussed in the context of struggling with new learning, or new experiences such as conducting an interview for the first time.

Countering these, some of the positive emotions described were: excitement; hope; enjoyment; and a sense of achievement. While many participants described feeling, at some stage in the process, that they had ‘had enough’, overwhelmingly, they stated that overall the experience of being a researcher was positive. For example Isis said: “if I sit and think, I’d end up saying the whole lot was great, even though there were ups and downs”. Walter echoed these sentiments also: “It’s good, it’s been a positive experience and it is a positive thing”, as did Mandrake: “overall my impression of my experience has been a favourable one. I look on the whole experience as being beneficial”.

Emotional experiences were not described as discrete and clear, but mixed and complex. For example, Susan, describing one of the more personally challenging interviews she conducted, relays both positive and negative emotions as accompanying this experience:

Susan: I just felt honoured that she was trusting me with this information.

Gillian: Yeah

Susan: And it was a bit shocking...

The emotions that accompanied these experiences interlinked with those accompanying other parts of life at times also:

Ruth: I felt stressed a lot of the time.... There were feelings of excitement here and there, but there were also feelings of a lot of stress, um, some of it was due to the actual work, but some of it was my personal situation.

Other participants' stories were similarly layered.

*Doing the Job versus the Rest of Life: the Context of Becoming a Researcher*

Working as, and becoming, a researcher clearly happens within a context for the participants in this study. They spoke about the general context of their lives, and at times, the more particular context of mental health and illness. Often, these two contexts were not clearly separate in participants' discussions, overlapping and intertwining. Participants reflected on both the struggles of fitting their work as researchers with other aspects of their lives, but also on the times where their work closely related and positively amplified other parts of their lives. For example, Mandrake reflected on the learning he felt occurring from his participation as a CR, and how this related to, and complemented his learning in the context of other study he was completing as part of another work role:

Mandrake: I'd stereotyped my beliefs before, and I see them now as more personal. And you know, what we're talking about here are people's needs, and how we can best facilitate those needs, and there's some work I'm doing, another course I'm studying for that brought that whole question of needs up

Gillian: aha

Mandrake: How do you facilitate need? and so that's all been sort of going on at the same time.

Gillian: that's also an interesting point for me, because something that I find coming up as people talk about their experiences is how what happens in our

project sometimes clashes with, sometimes mixes nicely with, whatever else is going on.

Mandrake: Yeah, well they seem to go really hand in hand. I've found that those two jobs occupy a lot more of my thinking time than my third job, which is just dealing with numbers [laughs]

Gillian: Mmm

Mandrake: accounting - bookkeeping I mean.

Gillian: yeah. And how have they all fitted, just in terms of practical life?

Mandrake: oh, I've been very busy,

Gillian: how have you balanced it?

Mandrake: well, actually, one of the um, the study course I'm doing with [my other workplace] has been put on the back-burner; I'm sort of two thirds through it. And um, well if the project starts to sort of ease back now, I should get an opportunity to finish that by June next year

Gillian: mmm

Mandrake: so, it's been pretty hard balancing them

Gillian: what's kept you balancing them? What's kept you going with so much stuff?

Mandrake: Oh, well, I'm still only working seventy percent of a full-time working week, in terms of hours committed. So I've got a bit of time up my sleeve.

For Mandrake, working as a CR appears to have held many positive features, however, at times this work has still meant other parts of his life have had to be placed on hold, or reorganised.

Susan also spoke about how this role related to other parts of her life, particularly her career aspirations and her relationships with family:

...that was very exciting because I had been unemployed for some time, and I really, you know, if you asked me what I'd like to do out of everything, what I'd like to do is work in the health area - the area of health. Because I'm a naturopath, and that's what, you know, what I'd like best to do, and that could be the most satisfying job I could have. But I'd be satisfied to have any work rather than nothing to do, but if I'm going to work, that's the most satisfying work I could have.... And I was very interested at the time because at the time I didn't have any work, really, except the odd bit of car wash, and I'd got to that stage of my recovery when I was really looking around for a bit of work, so I was really ready to grab it with both hands... telling people, you know, and saying I've got to go to work, and they say 'what do you do?' and I say 'I'm going to work at the University of Wollongong' [laughs]. It's really nice.

Gillian: Yep. So you got a real kick out of being able to tell people that's what you were doing?

Susan: Yeah, I did. And then people would ask me about my work, and I'd explain it to them and that, and that was a good little conversation-starter.

Gillian: yep. So really, it's had some very positive effects in your broader life, sort of being able to interact with other people and be able to say, 'this is what I do' 'this is what I'm doing' and people have been interested.

Susan: Yeah, and telling my mother about it as well. She's sort of had the feeling that I'm a bit of a no-hoper since I've been unemployed and mentally ill, and it's

nice to be able to tell her I'm doing good, and I'm sure she's told all the family.  
[laughs].

Becoming a researcher has meant making adjustments to other roles participants' play and enjoy. For example, one participant spoke of the difficulties she found in maintaining her work as an artist, which often meant working through the night, while also working on the project. Participants spoke about the challenge they felt, at times, of balancing work with other commitments, or focusing on work when other life issues became prominent. For example, Ann talked about her wish to be part of a conference presentation as a CR, but finding other work roles demanding her time, not allowing her to take part in the conference:

But then when the TheMHS conference was on last year I was working full time at [a public] hospital, in mental health. But, what I - at that stage I got bogged down with work commitments and I wasn't able to get away...I was working quite hard, and I didn't think I'd be able to actually go back and do the, um, part of the project again at that stage. Because I felt it was just too much for me to take.

The second context of mental health/illness, related to both their personal mental health, and the area of mental health more broadly. For example, when I asked San about his concerns when first thinking about applying for the CR role, he said:

San: um, just whether I'd get along with people, and whether I could handle my illness at the time, and still work- that's all

Gillian: Yeah.

San: And all the travel, if I could manage that.



Gillian: yeah. So really your concerns were about whether you'd be able to handle the different aspects of the job, as well as if your own experiences and illness plus work. And wondering what the team would be like and if you'd get along with them all.

San: yeah

Ann also spoke about her concerns regarding balancing the various aspects of her life, including being a CR, and how this would affect her mental health:

how am I going to go? was I capable of doing it? Was I capable of doing it with study was my next concern. I thought - and my concern was then, was I well enough to do both because would too much pressure of doing both send me unwell?

More positive impacts, perceived through the context of living as a consumer of mental health services were raised at times also. For example, San spoke about the opportunities he felt the project offered him, compared to the limited opportunities he normally found as a consumer, saying:

When somebody else's problems came up it was sort of like, I had to deal with that. It was sort of like good to get out and deal with other people's problems and not my own.

Gillian: Ok

San: normally as a consumer, sitting at home, you don't get that opportunity. This project has given me an opportunity to share

Walter also spoke about finding the project impacting in this sense, describing a feeling of personal reassurance:

Walter: It was quite enlightening and interesting to find people - it was interesting to find people who've had experiences with the mental health services...It was reassuring that people are coping; you know people are trying to cope. People are trying to come to some understanding even though they've been diagnosed with a severe illness.

Gillian: mhm. So was there a sense for you in part of that reassurance, that sort of, maybe the struggles that you've faced trying to work through that for yourself is something other people are going through and working out as well.

Walter: Yeah, that's right. Your own experience, that other people have their trials and problems with the mental health service, with their own people that come into contact with the mental health service too. So it's not just you, there are problems that other people have to work through too. It's interesting to hear other people's perspectives

Both of these positive impacts interlink with the sub-theme of *The importance of relationships versus isolation* described earlier.

#### *Playing an Active Role versus Not Being Engaged*

Some participants talked about the importance of the times in the project when they felt they began to play an active role – to be involved and be part of something. Often, critical points in the project participants highlighted during our discussions, and via their winding river charts, were times where they felt they were taking an active role. More broadly, this theme also relates to playing an active role at a wider social level. When participants felt they were not contributing to the level they desired, they described feeling more negative emotions:

San: And with the difficulty with the Evaluation Framework,

Gillian: mhm

San: the struggle there was getting paid, and trying to put something in. I felt like loyal, to the project I wanted to really earn my keep. And if I just wasn't understanding, I felt a bit guilty.

Gillian: Aha, so it was sort of feeling like you were there, getting the money, but not really feeling like you did contribute sometimes?

San: although, I'm sure I did contribute

Gillian: I'm sure you did too.

### *Growing Empowerment versus Power Imbalance*

This theme is about the issue of power. While becoming researchers, participants experienced both power and powerlessness within the project. For many, the project created a space in which they felt more empowered, and even at times an opportunity to challenge some traditional power imbalances faced. For example, San commented:

I felt a bit power imbalanced when I was around doctors and professionals at those [conferences]..., but when I participated in those meetings, it was like completely switched. I felt like I was contributing part of it instead of just tagging along, and those doctors and professionals I felt a bit intimidated by and isolated by, were listening to me and interested in what I had to say.

Isis's discussion about the experience of working on a conference paper with other CRs provides an interesting insight into the complexities of power relations within the research team:

I think because we didn't have someone like yourself, like an academic to tell us what to do it was good. We actually did it ourselves. So it was like, this is our own little project we can do. We had help there if we needed it, but this is a thing we did ourselves, for us, and the project, and put it out there on the Australasian stage. So that was really something we did ourselves. I think that was really important. Even though we had dramas and things!

Ruth's discussion about her views of the interviewing process for the CR positions also highlights the complex nature of how power within the team is perceived by participants:

Ruth: I've been involved in mental health a lot longer than [a consumer representative who interviewed Ruth for the position]. And I know she does things that I don't do, but um, I just thought, how can someone that hasn't been involved in mental health all that long suddenly be doing that [interviewing applicants for the CR positions].

Gillian: mhm

Ruth: that's just what I thought. So, if it had of been [another consumer representative] or someone like that, it would have been different. So I just think, maybe in future, ah...with interviews, I just think personally, just keep it to just the university staff that do the interviewing, in that sort of - not other than that, because of course the consumers are all part of it....I just felt that they have more, more - it's just right, it just felt right being interviewed by people running the project, not by another consumer.

Despite the complex nature of power balances and imbalances within the team, participants repeatedly used the term “empowerment” to describe the experience of becoming researchers. For example, San said:

the thing that I’ve been given – had - all this experience of talking to people about these issues, which I’ve never done before. And it was sort of like, I was a consumer researcher I wasn’t just a consumer anymore. It was a bit of empowerment.

Participants also described feeling a greater sense of personal power throughout their involvement, and because of their work, as Ann described:

I think at that stage I was starting to feel more powerful in the sense that ah, the consumers as a group, that this [the project] was happening, and they were having a say, whereas before I had a much dimmer point of view on the whole situation to do with consumers in the mental health system.

### Conclusions

In this chapter, I have described the responses participants provided in the focus group, discussing the relationship between the ten themes that emerged from Study 1 and their experiences becoming researchers. I have also described the themes that emerged from interpretation of their responses during the interviews, asking them about their experiences becoming researchers. Seven themes emerged from analysis of the interview data, which reveal the complex nature of the experience for the participants. In presenting these results, I have attempted to tell their story as much as possible through their own words. In the next chapter, I will discuss the results presented here and consider how these themes relate to other literature. I will use these themes in the next chapter to

address the Research Questions I have posed, to develop a clear understanding of the experience for consumers of becoming evaluation researchers.

## CHAPTER 12

### EXPERIENCES OF BECOMING A CONSUMER RESEARCHER: DISCUSSION

In this chapter I will discuss how the results from Study 2 presented in Chapter 11, along with the results from Study 1, presented in Chapter 8, address the remaining research questions guiding this inquiry. The results presented in Chapter 11 specifically answer Research Question 2: *What are the experiences of being a consumer researcher?* I will address this first, and will then consider the picture created by considering the two sets of results in combination, specifically focusing on the answer they provide to the remaining three research questions: *What is the nature of this transition, from consumer to consumer researcher? What emotions accompany this transition? and What changes in self-construing occur during this transition?* The answers to these research questions rely primarily on the results from Study 2, however will be supported at times by the findings from Study 1.

#### Understanding Consumers' Experiences of Being Researchers: Addressing Research Question 2

I described seven themes in Chapter 11, which resulted from analysis of the interviews conducted with consumers working as researchers as part of the CEO-MHS research team. These themes are listed in Table 20.

The experience of becoming a researcher was different for each participant, as the results presented in Chapter 11 demonstrate. However, the themes indicate the common experience also. For some of the consumers involved, this was their first paid job after a significant period of time. Only a few had been more actively involved in the paid work force recently. The features of being in work played an integral role in the experience of becoming a researcher for all CRs. For them, to be paid for the work they did, to have the opportunity to feel they were contributing to society, and to have a place to go were all



Table 20

*Interview Themes from Study 2 Interviews with Consumer Researchers*

## Study 2: Themes from interviews with Consumer Researchers

Having a job versus notThe positive and negatives of the work environmentBroadening personal horizons versus a narrowing world

- Self: personal growth
- Importance of relationships versus isolation
- Learning
- New experiences, new perspectives
- The unknown

The positive and negative emotional experiences of becoming a researcherDoing the job versus the rest of life: the context of becoming a researcherPlaying an active role versus not being engagedGrowing empowerment versus power imbalance

important aspects of the experience. The themes that emerged in Study 2 reveal the experience of becoming a researcher to be multifaceted and complex, accompanied by a plethora of positive and negative emotions, personal opportunities and challenges. The interlinking of a deeply personal journey with inherently social processes is highlighted in the themes resulting from interviews with CRs. Becoming and being a researcher was tremendously challenging but concurrently deeply rewarding and satisfying for these consumers, and linked intimately to their experiences living with diagnoses of mental illness.

There is a strong body of literature, spanning both the mental health field specifically, but also more general employment fields, which highlights the importance of work in people's lives (Goodwin & Kennedy, 2005; Harnois & Gabriel, 2000; Sane Australia, 2003). The stories of the consumers in this study support this body of literature, and the importance of work to the health and quality of life of mental health consumers. The seven themes presented here contribute to a deeper understanding of the experiences and meaning of work for mental health consumers, and complement themes found by Kirsh (2000) in her qualitative analysis of narratives of mental health consumers. Kirsh's (2000) themes were: the meaningfulness of work (including sub-themes of work as a contribution to society; work as distraction and 'normalisation'; and work as a challenge, achievement and self-worth); the impact of the organisation on job satisfaction (balancing challenge and predictability in search of satisfaction; psychosocial characteristics experienced at the workplace; needs and accommodations in the workplace); and the importance of supervisory and coworker relationships and attitudes (the influential nature of supervisors' and coworkers' qualities and behaviors; the dilemma of disclosure). Firm commonality between these and the themes presented in Chapter 11 is evident. The four themes found by Strong (1997) to frame the meaning of work in her ethnographic study also resonate with the themes found in Study 2.

These results also have central importance to the developing body of literature specifically relating to consumers' roles in mental health research, and their experiences of participating as researchers in the field. The themes described in Chapter 11 support and vastly expand the understanding offered by Reeve et al (2002) in their description of the experiences of being a consumer researcher. Relationships within the team and the

need to build trust, as well as the challenges of identity were also highlighted in their description. Additionally, the centrality of the experience to self-esteem development, the acquisition of skills, and a sense of meaning and purpose were highlighted in their research. These issues are raised also, in the themes presented here. While the description offered by Morrell-Bellai and Boydell (1994) is not as comprehensive as that offered here, or by Reeve et al (2002), their results also indicated the centrality of team relationships, and the linked self-esteem boost that comes for many consumers with working as researchers.

#### The Transition of Consumer to Consumer Researcher: Addressing Research Question 3

Data from both Studies 1 and 2 contribute to an understanding of the transition of consumer to consumer researcher. Firstly, exploring the two sets of themes and the links between themes from Study 1 and 2, it is apparent that both sets of themes are relevant to their experiences of becoming researchers. Examining the links between the two sets of themes reveals several areas of commonality, while areas of difference are also seen. The two sets of themes are presented in Table 21 below.

A range of common issues are evident, and participants' discussion in the focus group in Study 2 also provided strong support for the relevance of the themes raised in Study 1 for them. Issues of power and power imbalances, and the importance of relationships stand out as overarching themes linking the two sets of results. Other similarities are also evident, for example, there is a focus on the environment and broader context within both sets of themes; and the importance of being involved evident in Study 1 relates to the theme *Playing an active role versus not being engaged* from Study 2.

Table 21

*Comparison of Interview Themes from Study 1 and Interview Themes from Study 2*

Study 1: Themes from interviews with Mental Health Consumers	Study 2: Themes from interviews with Consumer Researchers
<u>Acceptance versus stigma</u> <u>Highly informed and educated versus poorly informed and educated environment</u> <u>Power and powerlessness</u> <u>Consumer involvement versus lack of consumer involvement</u> <u>Optimal and appropriate versus inadequate and inappropriate medication experiences</u> <u>High versus low service quality system</u> <u>Responsive/unresponsive to consumers</u> <u>Satisfying versus dissatisfying relationships with staff</u> <u>Supportive or unsupportive of relationships with community, family and other consumers</u> <u>All of me versus me as an illness</u>	<u>Having a job versus not</u> <u>The positive and negatives of the work environment</u> <u>Broadening personal horizons versus a narrowing world</u> <ul style="list-style-type: none"> <li>○ Self: personal growth</li> <li>○ Importance of relationships versus isolation</li> <li>○ Learning</li> <li>○ New experiences, new perspectives</li> <li>○ The unknown</li> </ul> <u>The positive and negative emotional experiences of becoming a researcher</u> <u>Doing the job versus the rest of life: the context of becoming a researcher</u> <u>Playing an active role versus not being engaged</u> <u>Growing empowerment versus power imbalance</u>

Through the exploration of the relationship of themes from Study 1 to participants' own experiences, during the focus group in Study 2, they considered the themes from Study 1 as having underlying relevance to the experience of becoming a researcher. For example, while a theme equivalent to the one focusing on medication in

Study 1 did not emerge in analysis of interview data from Study 2, participants unanimously expressed the importance of the issues surrounding medication as fundamental to their experiences both generally and specifically in becoming researchers.

While accord between both sets of themes can be seen, it appears that the themes in Study 2 often directly complement the deficiencies raised by themes in Study 1. I noted in Chapter 9 the parallels between the themes that emerged in Study 1 and themes from the recovery literature. It appears from exploration of the connections between themes from Studies 1 and 2 that the experience of becoming a researcher provided opportunities for participants to address some of the issues important in their journey of recovery. For example, while in Study 1 a sense of being powerless was the overwhelming feature of the theme *Power versus powerlessness*, in Study 2, consumers' stories were strongly reflective of a growing sense of personal empowerment. As Carrick, Mitchell and Lloyd (2001) discuss, power relations in collaborative research are not unambiguous between researcher and participants, and while creating opportunities for empowerment is often an aim of collaborative research, there is no guarantee that participation will result in increased empowerment for consumers. Power is typically understood in terms of consisting both of actual and perceived aspects (Carrick et al, 2001; Riger, 1993; Zimmerman, Israel, Schulz & Checkoway, 1992). Because research can and does have real world implications (Parker, 1994; Smail, 1994), it relates to both actual power as well as perceived power.

Similarly, a sense of personal growth and change marks the results of Study 2, particularly communicated through the theme *Broadening personal horizons versus a narrowing world*, whereas the data in Study 1 reveals a sense of yearning for

opportunities where this personal growth and change can occur, evident in the theme *All of me versus me as an illness*. It appears that the transition from consumer to consumer researcher has many elements that feature in descriptions of recovery (Davidson & Strauss, 1992; Deegan, 1988 & 1996; Ralph, 2000; Ridgway, 2001). For example, the themes I found from Study 2 are reflected in Ridgway's (2001) analysis of four first-person accounts of recovery, most particularly resonating with her themes: recovery is moving from withdrawal to engagement and active participation in life; recovery is active coping rather than passive adjustment; recovery is moving from alienation to a sense of meaning and purpose; recovery is not accomplished alone – the journey involved support and partnership; and recovery is the reawakening of hope after despair.

Fisher (1996/7), the Executive Director of the National Empowerment Centre in the USA, uses the metaphor of a tree to define and explore the concept of recovery. He describes the ground as shared humanity; the seed of the tree as spirit; and the roots, connections. Fisher describes the trunk of the tree as body, mind and soul, with branches being a sense of self and voice. Using Fisher's metaphor, the limbs of the tree reach out to give fruit to self and others: love, courage, self-esteem, pride, hope and meaning. This metaphor is helpful in considering the experience of being a consumer researcher, as described by participants in my second study, and how the themes that emerged can be conceptualised as part of the recovery journey. The research team, and the values held by the team are like the ground, the shared humanity and the seed of the tree, the spirit. The relationships that formed within and beyond the team are the roots, the connections. The people that came together, with all their uniqueness, forming the team are the trunk: mind, body, soul. The work that was conducted – the communication, the storytelling –

can be conceptualised as the branches, reaching out to the limbs and the fruits that were both individually felt, and shared: a sense of personal empowerment, companionship and friendship, a sense of greater self-esteem, skills that can be applied to other areas of life, a sense of purpose and meaning.

As consideration of the remaining two research questions addresses, the transitional experience involved a range of emotions, and changes to the way participants construed themselves. It challenged participants to different extremes, but resulted, for all from their accounts, in some change in their construct systems. Overall they reported that the experience was positive. Danley and Ellison (1999) similarly report that consumer members of a participatory action research team reflected on their enjoyment of the experiences, particularly because they were actively involved. They suggested that this “fostered a sense of accomplishment, a sense of competence, an appreciation for the experiences and learnings they brought to the PAR team, along with the development and utilization of skills.” (Danley & Ellison, 1999, p. 21).

As the sub-theme *the unknown*, part of *Broadening personal horizons versus a narrowing world* reveals, much of the experience of becoming researchers was unpredictable for the participants. As Walter so clearly indicated, researchers felt their construct systems did not provide them with adequate sets of meanings to understand and anticipate, particularly in the initial stages of their work on the project. In parallel, participants described an environment where relationships were strong and central, where they felt supported by other team members, and where they experienced and contributed powerfully to a strong ethos of non-judgment. Within personal construct psychology, the sense of “the unknown” indicates that transition – or change – is likely. As I described in

Chapter 3, the theory anticipates that when faced with a situation where they are unable to anticipate, participants are likely to reconstrue or develop new constructs with which to understand this new aspect of their world.

The accounts by participants in Study 2 also indicate that an aspect of the experience of transition from consumer to consumer researcher involves structural change to their systems of meaning. In Chapter 4, I suggested, based on the work of Neimeyer and others (1988, Nevill, Neimeyer, Probert, & Fukuyama, 1986), that the concepts of cognitive integration and differentiation together provide a useful framework for considering general changes in systems of meaning that occur during work transitions. Neimeyer et al's model indicates that as participants in Study 2 have continuing experiences as consumer researchers their construing systems will become increasingly complex. Susan, describing one challenging stage of her work as a CR, indicates the process of increasing differentiation and integration of her construct system occurring as she took part in work as a CR:

it was as if I was doing a sum, or an equation - arithmetic or something. And I had no idea how to approach the problem and that was the overwhelming part...And then finally you had the process, you know, you've got the formula or something.

And you know then that  $c=2$ , ah! Well, if  $c=2$ , the whole sum means something.

Ann too, describes integration of her construct system taking place, as she told me her reaction to the experience of interviewing other consumers as a CR, and the implications this experience had for her in her role as a mental health clinician:

I [started to] think, why haven't I been doing that in my role as a health professional, why don't I - you know - put an equal footing as a consumer and



interview from that perspective, rather than from a more impersonal perspective. So I've learnt that...After I'd done the interviews [as a CR] and went back to work, I tried to do that. And that was a really different interviewing process I used, totally, from that before. And they were - the people - were far more responsive to that kind of approach. It was really rewarding, and I felt like saying 'listen here you world of mental health clinicians, do it this way, you'll be right'. Another example of increasing complexity, through integration of his construct system, is provided by Mandrake:

it has something to do with - I don't know how to tie this in, but my belief system. I started to take a fresh look at my belief system. I started to think more - less, less about a corporate belief and more about a personal belief...I don't know whether you can do that - but I started to take into account more and more what my beliefs meant to me and what value it had in my life.

In each of these examples, participants are describing situations where their ways of understanding the world around them are reorganised: with ideas and meanings being related in new ways as their meaning systems form fresh and differing hierarchies and alternative constructs achieve superordinacy to better makes sense of the world based on their new experiences.

#### The Emotions of Transition: Addressing Research Question 4

According to personal construct theory, emotion is the experience of change, or recognition of its imminence. Emotion was found to be a clear accompaniment to transitions, as I described in Chapter 4 (Adams, 1976; Hopson & Adams, 1976; Johnson & Robson, 1999; Viney, 1980). A range of emotions clearly accompanied the experience

of becoming researchers for all participants, as evidenced by the emergence of the theme *The positive and negative emotional experiences of becoming a researcher* in Study 2. The theme interconnected with most of the other themes, indicating the embedded nature of emotion in the experience of becoming a researcher.

Within the consumers' narratives, emotions such as anxiety and confusion were expressed when they described "the unknown" and unexpected nature of becoming a researcher. While these emotions were strong at the commencement of their roles as researchers, they were also described by participants at a range of points throughout their experiences becoming researchers. As participants faced research tasks that were new to them during the project, feelings of anxiety and uncertainty were experienced. One of the markedly shared times this occurred after the initial stages of the project was during their work to develop the evaluation framework, which occurred throughout the third, and final year of their work. They related feeling strong anxiety and confusion accompanying difficulty in processing the complex and abstract subject matter involved in this task. Within the theory of personal constructs, anxiety is defined as "the recognition that the events with which one is confronted lie outside the range of convenience of one's construct system" (Kelly, 1991, p. 365).

As well as the negative emotions experienced, participants clearly described positive emotions accompanying the transition. As highlighted by the theme *The positive and negative emotional experiences of becoming a researcher* participants described experiencing feelings of excitement, pride, sense of achievement, enjoyment, and hope. These positive emotions have been identified as central to experiences of recovery (Czuchta and Johnson, 1998; Davidson and Strauss, 1992; Deegan, 1988; Mead &

Copeland, 2000; Murphy, 1998). Within personal construct theory, positive emotions are viewed as relating to awareness of construct validation (McCoy, 1977). The positive emotions CRs described are consistent with McCoy's description of happiness, which relates to validation of part of a person's core structure, and satisfaction, which relates to validation of non-core structure. The growing self-confidence participants described indicates that through their research roles they came to see themselves as more integrated, given McCoy's definition of self confidence as awareness of the goodness of fit of the self in one's core role structure.

The positive emotions described by participants add an important dimension to the understanding produced by participants' description of negative emotions. Although participants experienced some discomfort, evidenced in descriptions of anxiety and confusion, the experience of becoming CRs, for these participants also functioned to confirm their meanings about themselves, and from the description of emotions provided, this appears to have occurred at both core and non-core levels.

#### Changes in Self-Construing: Addressing Research Question 5

The emotions of transition described above indicate strongly that some self-reconstruction was likely during the experience of becoming a researcher for the consumers involved. The theme of *Broadening horizons versus a narrowing world* and its sub-themes also indicate clearly that there were changes in self-construing for participants.

Discussion regarding self-esteem and confidence, and the theme of *Growing empowerment versus power imbalances* indicate that changes were towards seeing themselves as more capable, valued, and confident, with a greater sense of place in the

world, through their roles as researchers and the opportunities for expansion this provided. Participants clearly found the process of being involved as researchers one that challenged their constructions of themselves, and several participants described clear reconstruction. This type of self-reconstruction is reflective of that described in the recovery literature (Davidson & Strauss, 1992; Provencher, Gregg, Mead & Mueser, 2002).

The reconstruction that occurred links to the environment and the relationships created within the research team. Support, according to Kelly (1991/1955), encompasses a broad response pattern that permits receivers to experiment widely and successfully. Support is essentially about confirming the other's processes of construing. So, from a personal construct perspective, support lies in validation of people as construers of meaning. Support can be derived from sharing common constructs for interpreting experiences (Duck, 1973, 1979) and meanings (Neimeyer & Hudson, 1985; Neimeyer & Neimeyer, 1983). Understanding in terms of acknowledging the others' way of seeing things is necessary, however, as well as similarity, for supportive relationships (Kelly, 1991/1955). This type of support was actively attempted by myself and others in the research team in our interactions. The role people's perceptions of their social support play in mediating experiences of transition is highlighted in Viney's (1980) phasic model of transition, reviewed in Chapter 4.

It was within the support of the environment created, and the relationships of the team, that participants felt able to not only engage with the challenges posed by becoming researchers, but as well, at times, create further challenges for themselves. Isis, for example, spoke about her decision to create further personal challenges by choosing

to travel as part of her role as a CR, something she had previously found difficult. In personal construct terms, this is an example of aggressiveness: she was actively seeking to elaborate her perceptual field. The research team itself (most centrally, the Consumer Researchers, the Project Officer and myself) provided a rich source of validation and invalidation for CRs construing – both old and new constructs. With the exposure their new roles as researchers provided to novel experiences and different perspectives, participants approached the challenges of “the unknown”, finding new and alternative ways of seeing themselves in the process. Participants were provided with a new, and strong environment for validation or invalidation of their self-constructs, and from the interview data it is evident that participants experienced invalidation of some of the more negative self-constructs they had previously held, as well as validation of other more positive construing. For example, Martin related changes occurring in his view of himself because he was working in an environment where his perspective was requested and valued. Mandrake relayed having to reconsider his meanings about his own mental health history after becoming involved in the project and being exposed to new ways of understanding and approaching these issues. Susan spoke about how interacting with the research team changed her view of herself in social settings, and she began to view herself as more equal and capable in social environments. Social support has been linked to a number of health and mental health outcomes in the general population (Rogers, Anthony & Lyass, 2004), and Rogers et al (2004) found that social supports play an important role in vocational performance and experiences of psychiatric symptoms.

An interesting example of change in self-construing was provided by Nic when he related what appears to be his active attempt to engage in non-validation, rather than

testing his construing of himself by choosing not to volunteer to facilitate a focus group. As he spoke about this, initially he suggested that his construction had changed because he started conducting interviews. As he verbalised this, however, he realised his constructs must have shifted before he conducted interviews, to allow him to take the risk of volunteering to do so. Nic began to reconstrue his meanings of success and failure. He was apparently ready to test a construct system where success and failure were no longer held as poles of one construct: a previously held construct that appears to have been quite central to his view of himself. Clearly, he had begun to apply different construing to himself also.

On consideration of what the data from Study 1 adds to an understanding of changes in self-construing, the themes that emerged from these interviews indicate a construction of self as powerless. One of the changes evident, when considering these two sets of data, is the different construction evident in the themes from Study 2, which I have labeled *Growing empowerment versus power imbalance*. In Study 2, participants' discussions of themselves reflect a stronger sense of personal control and power, and evidence of opportunities to experiment with traditionally power imbalanced relationships.

Personal construct theory places interpersonal relationships centrally to self, and personal change (Kelly, 1991/1955), and the research team and the interactions and relationships within it were central to participants' expressions of their experiences. Participants experienced validation of their construing within the team, and found strong commonality, but also respect for their individuality within the team. This was a critical aspect of the transition that occurred for participants. Within the team of other consumers

and academics, a shared social reality developed, and a secure environment for participants to understand and make sense of their worlds.

### Conclusions

Only a few studies exist that explore the role of mental health consumers as researchers, and what the experience of becoming a researcher involves for mental health consumers (Henry et al, 2002; Morrell-Bellai & Boydell, 1994; Reeve et al, 2002). While there is an expanding recognition of the need for consumers to be fully involved in mental health research, the limited understanding of what it is like for consumers to become researchers has meant that opportunities for this role to develop have been somewhat limited. In this chapter I firstly considered the answer the data from Study 2 provides to Research Question 2: *What are the experiences of being a consumer researcher?* I then considered how the data collected in Studies 1 and 2 combine to address the remaining three research questions, which relate to the nature of the transition; the accompanying emotions; and changes in self-construing that occurred during the transition.

In the next chapter of this thesis, I will review the findings from Study 1 and Study 2. Using the data and the framework provided by a personal construct theory consideration of transition I will propose a model of the experience of mental health consumers becoming evaluation researchers.

## CHAPTER 13

A MODEL OF THE EXPERIENCE OF MENTAL HEALTH CONSUMERS

BECOMING EVALUATION RESEARCHERS



In this chapter, my aim is to propose a model of mental health consumers becoming evaluation researchers, based on the findings from Study 1 and Study 2, and using personal construct theory as the guiding framework. I will begin by reviewing the research presented in this thesis and follow with proposing the model.

### A Review of the Research

In reviewing the literature about evaluation and research in the mental health field (Chapter 2), it was evident that, while there is a growing call within this field for consumers to be actively involved in evaluation research, there are few published examples of this occurring. Less information is available exploring the psychological experience of becoming a researcher for consumers. The importance of having work and the role work can play in enhancing mental health is widely acknowledged (Harnois & Gabriel, 2000; Kirsh, 1996; Sane Australia, 2003) and several authors have focused on exploring what work means to consumers of mental health services (Kirsh, 1996; 2000; Schneider, 1998; Strong, 1997).

The research I conducted began working with the team of CRs who participated in Study 2 on the CEO-MHS project, and our growing awareness that describing and understanding their experiences in becoming researchers was an important aspect of the project to capture and share. This research adds to both the literature relating to consumers' roles in research, and consumers' roles in work more generally.

In Study 1, using accounts by consumers of their experiences with mental health services, I explored what it is to be a consumer of public mental health services. I wanted to understand this specifically, to assist in developing an understanding of the experiences for consumers becoming evaluation researchers. I considered the experience

of being a consumer as an important component of the larger picture to explore. The Research Question that guided this study was: *What are the experiences of being a consumer of public mental health services?* The focus groups and interviews, which CRs conducted, provided rich sources of information, allowing the participants to voice their personal understandings of what it is like to use mental health services, and live with a diagnosis of mental illness. The approach we took to interviewing was informed by the findings from the focus groups. This meant that themes from the focus groups were used to construct the interview guide, and so themes from focus groups were explicitly used in the second phase of Study 1. The themes found from analysis of interviews reflected the themes from focus groups, but also new information, or alternative understandings of some of the issues already raised. The themes that emerged from Study 1 were: acceptance versus stigma; highly informed and educated versus poorly informed and educated environment; power and powerlessness; consumer involvement versus lack of consumer involvement; optimal and appropriate versus inadequate and inappropriate medication experiences; high versus low service quality system; responsive or unresponsive to consumers; satisfying versus dissatisfying relationships with staff; supportive or unsupportive of relationships with community, family and other consumers; and all of me versus me as an illness.

I devised Study 2 to understand the experiences of the Consumer Researchers in the CEO-MHS team, with the aim of examining their personal experiences of becoming evaluation researchers. Again in this study, the focus group and interviews provided an important opportunity for participants to voice their understandings of their experiences, and in fact, when it occurred throughout the results presented, their own reconstruing of

events as they told their stories. As well, these methods produced a rich source of information with which to examine their experiences. Study 2 was guided by one primary Research Question: *What are the experiences of being a consumer researcher?*

My analysis of the data collected during Study 2 resulted in clear validation from CRs of the relevance of themes from Study 1 to their experiences of becoming consumer researchers. Additionally, seven other themes emerged, which were: having a job versus not; the positives and negatives of the work environment; broadening personal horizons versus a narrowing world; positive and negative emotional experiences of being a researcher; doing the job versus the rest of life: the context of becoming a researcher; playing an active role versus not being engaged; and growing empowerment versus power imbalance.

I had also posed three further research questions, to assist with my aim of better understanding the nature of the experience of becoming an evaluation researcher, for consumers. I addressed the final three research questions using the combined findings of Study 1 and Study 2. These research questions were:

*What is the nature of this transition, from consumer to consumer researcher?*

*What emotions accompany this transition?*

*What changes in self-construing occur during this transition?*

Using the themes from both Study 1 and Study 2, I described in Chapter 12 that the nature of the transition from consumer to consumer researcher appears to be one of recovery, in that it was described as a journey of the development of hope, creating purpose and meaning, an active stance in life, and personal growth and empowerment. These changes did not preclude a range of emotions being experienced, which is

consistent with the concept of recovery. Consumers who have written about recovery describe the recovery journey as constituting a full range of both positive and negative emotions (Deegan, 1995; Ridgway, 2001). Consumers in Study 2 experienced both positive and negative emotions. They described themselves as more confident, with a greater sense of self-esteem because of their roles as researchers. In general, the changes in self-construing that occurred during the transition to consumer researcher related to seeing themselves as more capable, valued and confident with a greater sense of place in the world through their roles as researchers and the opportunities for expansion these provided. Anxiety was the most prominent negative emotion, which is consistent with the amount of personal growth – or construct change - that CRs described. Participants also told of highly unique reconstruing that occurred during this transition.

#### Using the Data from Study 1 and Study 2 to Propose a Model of Mental Health

##### Consumers Becoming Evaluation Researchers

One function of a conceptual model is to prevent researchers, clinicians, and in this situation, consumers, from being overwhelmed by the complexity of both theory and the phenomenon that the model has been developed to describe. The goal of a model is, therefore, to convey a maximum amount of relevant information as simply and coherently as possible, to assist people's understanding of the particular area under scrutiny (Viney, 2001). A model needs to cover a range of issues relevant to the phenomenon of interest, and be, at the same time, specific enough to allow predictions based upon the propositions of the model (Viney, 2001). Models are similar to theories, however narrower, and apply the ideas of a better known domain to one that is lesser known (Viney, 2001; Harre, 1961).

I have aimed to develop a model, primarily informed by the data collected in Study 1 and Study 2, and supported by personal construct theory, to describe the psychological and experiential process, for mental health consumers, of becoming an evaluation researcher. Descriptive models aim to depict regular patterns in observed data (Miller-Day & Dodd, 2004). The purpose of this model is to assist consumers who may be interested in becoming researchers, and existing researchers in clinical and academic settings, to understand and anticipate better the process consumers new to research will experience in becoming researchers. Additionally, this model aims to assist others, such as clinicians, family and carers to understand the experiences of those consumers who choose to engage in research, as the area continues to grow. In turn, this greater understanding will assist in more genuine and successful opportunities for consumers to take on researcher roles. The model may also be useful in validating consumers' experiences.

Answers to the research questions that have guided this enquiry support the theoretical assumptions I have made: that the experience for Consumer Researchers working on the CEO-MHS project would be transitional. There is evidence from the themes that emerged from Study 2 that CRs experienced the emotions of transition, and changes in their self-construing, as part of their experience of becoming researchers. This is further supported by comparing the themes from Study 1 to those from Study 2.

While theoretical assumptions about transition have helped frame this research and guided development of the research questions, I have provided a data-driven, qualitative analysis of the data from both Study 1 and Study 2, before considering the answers these findings provide to the more theoretically derived questions. I will now

propose a model of transition, of mental health consumers becoming evaluation researchers, drawing from the data and the theoretical base of personal construct theory.

The data in Study 1 produced a detailed picture of the experiences of being a consumer of public mental health services. Analysis of these data resulted in 10 themes. Consumer Researchers, who participated in Study 2, considered the relevance and relationship of these 10 themes to their experiences becoming researchers. The results of this focus group were strong agreement between CRs that the 10 themes from Study 1 hold considerable importance in their process of becoming researchers. It appears from their discussion, that the themes from Study 1 could be viewed as general factors that need to be addressed by consumers in their lives. The convergence between the themes we identified in Study 1 and themes from the recovery literature supports this contention. These themes relate closely not only to the experience of using mental health services, but more generally to the experience of being diagnosed with a mental illness: what this means personally, socially and in their communities. Participants in Study 2 indicated clearly that each of the 10 themes from Study 1 played a role in the way they developed as researchers, and the way they experienced becoming researchers.

This leads me to my first proposition:

Proposition 1:

*Consumers bring to the experience of becoming researchers, a system of meanings which have been defined and elaborated during their experiences using and interacting with mental health services.*

Based on the data cited here from Study 1 and Study 2, I anticipate that for consumers facing the new challenge of becoming researchers, the construing brought to

this new experience will include a focus on the following: acceptance versus stigma; highly informed and educated versus poorly informed and educated environment; power and powerlessness; consumer involvement versus lack of consumer involvement; optimal and appropriate versus inadequate and inappropriate medication experiences; high versus low service quality system; responsive/unresponsive to consumers; satisfying versus dissatisfying relationships with staff; supportive or unsupportive of relationships with community, family and other consumers; and all of me versus me as an illness. These are the ten themes that emerged from Study 1, and which CRs in Study 2 validated as central to their experiences becoming researchers.

Interviews with participants in Study 2 resulted in a set of seven themes which provide a comprehensive picture of the experiences for these consumers becoming evaluation researchers. It is evident from these themes that a range of issues are relevant in the experience of consumers becoming researchers: this occurs within the context of the rest of their lives at that time, as well as the context of their mental illness and health experiences. As well, the work environment, and the benefits and stressors of having a job impact on their experiences. This leads me to my second proposition:

Proposition 2:

*The experience of becoming consumer researchers occurs within the context of broader lives.*

Generally, the experience of becoming researchers for these participants was described as positive, however, this did not mean that participants did not talk about times of difficulty: uncomfortable emotions which accompany transition were experienced by participants, and they described the experience of working on the

research project as personally challenging, often due to the experiences they faced as researchers being beyond their range of convenience. The next proposition, then, relates to the recognition that the research situation is beyond their range of convenience, by consumers new to research.

Proposition 3:

*When consumers engage with a research project, they are likely to hold only few clearly formed expectations that are quickly disconfirmed by the experience. Consumers quickly recognise that the situation is beyond the range of convenience of their current meaning system.*

While the to them, “well known” experiences of being a consumer of mental health services, shown in the themes from Study 1, form the initial context for becoming a researcher, the experience of becoming a researcher was marked by “the unknown” for participants in Study 2. These participants described not knowing what to anticipate, or reflected on how their expectations proved inadequate once they became involved as researchers, quickly being invalidated. These reports indicate that they recognised the experience of working as a researcher as beyond their range of convenience at that time, and so found they faced the need to develop new meanings or apply existing meanings to this new situation. As they faced this situation, being aware that their existing constructs did not assist them to anticipate, participants experienced the emotions of transition, most markedly, anxiety. This is evident in the theme *The positive and negative emotions of becoming a researcher*. Kelly (1991/1955) defined anxiety as a pre-condition to change in meanings. Participants, however, related finding themselves in situations beyond their range of convenience throughout the project: new research tasks sometimes proved to be



novel experiences to which their old meanings did not readily apply. Participants cycled then, at different times and frequency, between facing situations beyond their range of convenience, thus experiencing emotions of transition, and facing situations to which their meaning systems usefully applied. The following two propositions I propose relate to these emotions of transition and the reconstruction experience.

Proposition 4:

*Consumers will experience anxiety as they face situations in becoming researchers that they recognise as beyond the range of convenience of their current meaning system.*

Proposition 5:

*Faced with the challenges of a situation beyond their range of convenience, but perceiving the support of the team, and the new opportunities of having a job, CRs elaborate new meanings with which to understand themselves and anticipate this new aspect of their lives.*

Participants had to develop new meanings, or apply other meanings to the new elements they faced. The environment and relationships of the CEO-MHS project provided a fertile ground for participants to face the task of reconstruing. As I have shown in Chapter 12, participants spoke very clearly about the importance of the relationships that developed within the research team, and the support they experienced in these interactions.

Supportive relationships, from a personal construct perspective, involve both commonality and sociality, and are aimed primarily at helping the other elaborate their construing and move towards optimal functioning. Koch (1985) suggests that the elaborative potential of a relationship is governed by the level of commonality, which

provides confirmation of important meanings, and sociality, or the level of understanding which provides for elaboration of those meanings. Commonality relates to the potential for sharing of common understandings. These understandings provide experience of consensual validation of the individual view/experience. These processes also provide them with a psychologically secure context in which to elaborate their new meanings (Koch, 1985). Sociality, however, implies that relationships are limited by the degree of understanding that is attempted. Koch (1985) has suggested that the ability to experience recurring cycles of commonality and sociality are key features of psychological well-being. This leads to the sixth proposition of my model.

Proposition 6:

*Consumers will construe, test, and reconstrue their experiences of being researchers, and their self-construing, based on the experience in negotiation with others. Much of this reconstruction will be within relationships of the research team.*

Relationships within the team were a central component of the CRs experiences, and opportunities for commonality were fostered by bringing a group of consumers together. While individuality cannot be overlooked, the strength of a sense of commonality for consumers resonates within both sets of findings in this research. Trying to understand the meaning systems of others was actively encouraged within the team, and was one of my personal aims. We regularly discussed support together, and actively sought to attempt to understand each other's perspectives.

Participants in Study 2 showed evidence at times of actively choosing paths in their own research development and involvement in the CEO-MHS project that

challenged them, and provided them with novel experiences. This leads me to the seventh proposition.

Proposition 7:

*At times, consumers may choose to use their experience of becoming a researcher to actively elaborate their meaning system by choosing research tasks, or roles within the research team that are new, and which they anticipate will be beyond the range of convenience of their construct system.*

The seven themes that emerged in Study 2 share some similarities with the themes identified in Study 1. However, these reports demonstrate that the participants experienced change in the way they view themselves and the world through their experiences working on the CEO-MHS project. These changes related also to their personal sense of empowerment, and perceptions of power imbalances. I noted in Chapter 12 how similar the themes raised in Study 2 are to the tenets of the recovery literature, reflecting these changes in sense of empowerment, personal power, and overall a sense of personal growth and development, and achievement – or hope.

Psychological growth, from a personal construct perspective, is described by the Experience Cycle: the process of commitment (anticipation and investment), encountering, confirming or disconfirming and constructive revision (Epting & Amerikaner, 1980). Hope is also closely tied to engagement and completion of cycles of experience, in that to engage in successive cycles of experience means also to be open to experience, willing to engage in the encounter, and be prepared to anticipate a future. (Epting & Amerikaner, 1980). An additional consideration in understanding growth from a personal construct perspective is the structural development of their construing systems. Systems of meaning can be viewed as developing

along a continuum of simple to complex (Neimeyer et al, 1985; Nevill et al, 1986), through differentiation and integration. As I described in Chapter 12, the results from Study 2 demonstrate CRs developing increasingly complex (more differentiated and integrated) construing systems through their experiences of becoming researchers. This leads me to make my final proposition.

Proposition 8:

*When consumers elaborate new meanings they will experience growth and hope, reflecting completion of cycles of experience.*

A diagrammatic illustration of the model is presented in Figure 1

### Conclusions

In this chapter I have reviewed the research I conducted and discussed the major findings. I then proposed a model of mental health consumers becoming evaluation researchers, based on these findings and using personal construct theory to assist my conceptualisation of them.

The model I have proposed is informed by my interpretations of the data from the two studies I conducted and personal construct theory. The model proposes that consumers new to research will bring with them a set of constructs that have been defined and elaborated during their interactions with their worlds, but particularly with mental health services, and that these constructs will be important in their experiences of becoming researchers. The encounter with the research role will be one that is beyond the range of their current meaning systems, being a series of new situations for the consumers. As they recognise these gaps, they will experience emotions of transition, most markedly anxiety. In parallel, the research team relationships will be developing and

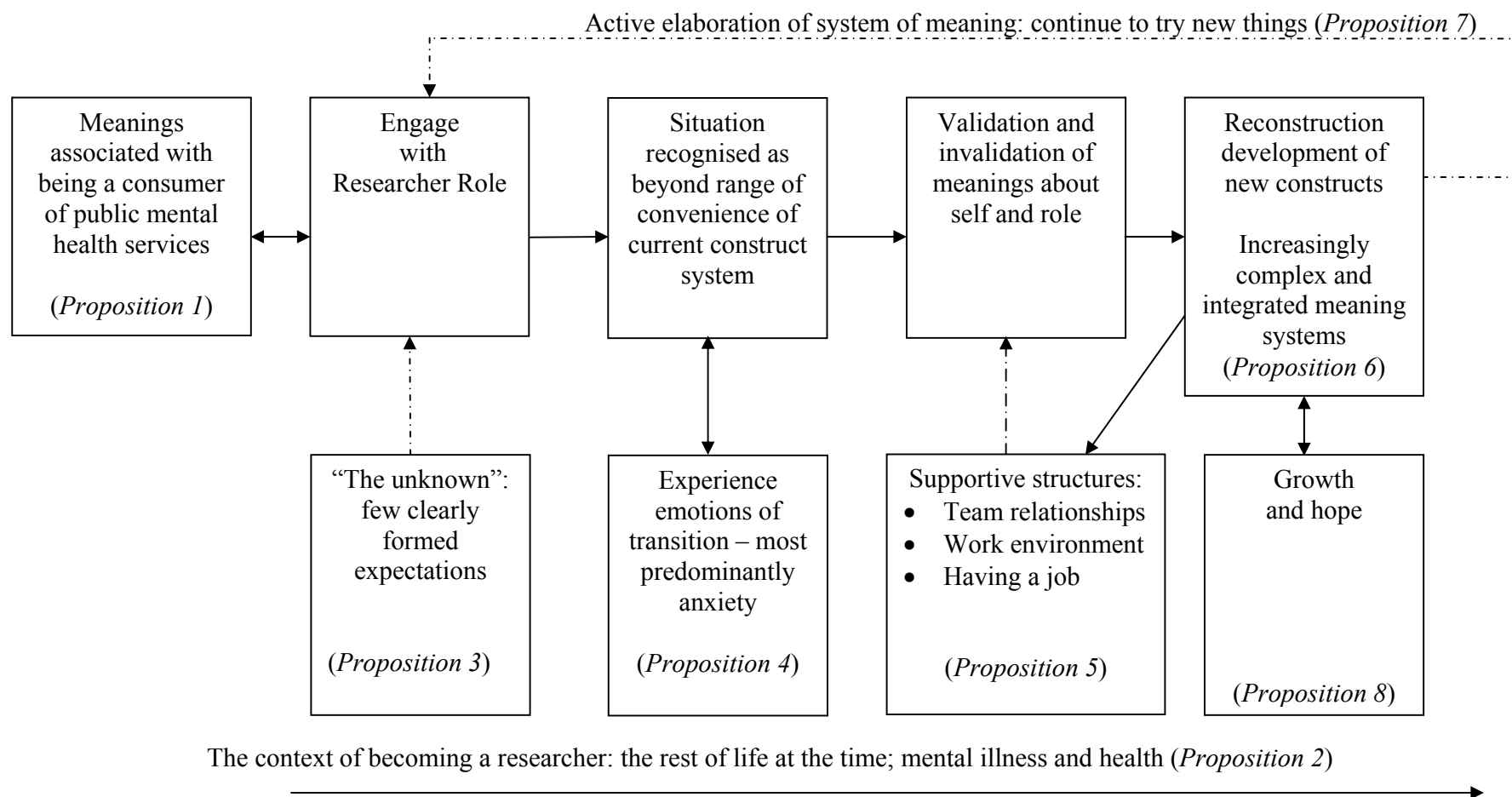


Figure 1. Proposed model of mental health consumers becoming evaluation researchers

these are a source of both validation and invalidation of their current construing. As well, the situation is marked by meanings associated with “having a job” and the practical and personal aspects of this for the consumers. From these parallel experiences, consumers will develop new constructs to help them make sense of their experience of becoming researchers, and of themselves. A sense of personal growth, hope and empowerment will be experienced as consumers elaborate new meanings. As they face new research tasks, consumers will at times find themselves once again facing situations beyond the range of convenience of their construct systems and so generating some negative emotions, and so will continue to cycle through this process.

In the following final chapter, I will draw together the findings, and discuss the implications, limitations and directions for future research raised by my research.

## CHAPTER 14

CONCLUSIONS ABOUT THE RESEARCH ON MENTAL HEALTH CONSUMERS

BECOMING RESEARCHERS

In this final chapter I will first discuss the implications of the research I have presented in this thesis. I will then consider the limitations and quality of the research, and draw conclusions regarding directions for future research based on my findings.

My overriding aim in conducting this research was to develop a better understanding of the experiences for mental health consumers new to research, in becoming evaluation researchers. Despite the increasing recognition of the importance of consumer involvement in research, to date few studies have been conducted exploring consumers' experiences as researchers (Henry et al, 2002).

In Study 1, my aim was to understand what the experiences of being a consumer of mental health services are, as I saw this as an essential backdrop to understanding the experiences for them in becoming researchers. I discussed the implications of Study 1 in Chapter 9, and I will briefly review these in the following section of this chapter.

In this chapter I concentrate on examining the implications of the research from both studies in relation to my overall aim. I have chosen also to consider the limitations and quality, as well as the directions for future research for both studies together in this chapter, for several reasons. Firstly, my intention in conducting both studies has been to contribute to an understanding of consumers' experiences of becoming evaluation researchers. This is reflected in the nature of the research questions guiding the studies, and that I considered the results from both studies in addressing three of the five research questions. I therefore believe it is necessary to consider the implications, quality and future directions from the perspective of this overall aim. Additionally, I believe that because the qualitative methodology used in Studies 1 and 2 was based on common



epistemology and similar methods, considering the quality of the two studies together is more parsimonious than attempting to conduct this separately for each study.

### Implications of the Findings from Study 1 and Study 2 and the Proposed Model

The findings from Study 1 produce a number of implications for mental health service provision and evaluation. Ten themes were identified from the data collected in Study 1: acceptance versus stigma; highly informed and educated versus poorly informed and educated environment; power and powerlessness; consumer involvement versus lack of consumer involvement; optimal and appropriate versus inadequate and inappropriate medication experiences; high versus low service quality system; responsive/unresponsive to consumers; satisfying versus dissatisfying relationships with staff; supportive or unsupportive of relationships with community, family and other consumers; and all of me versus me as an illness. These themes produce a rich tapestry depicting the key features and experiences of being a consumer of public mental health services. In Chapter 9, I explored the links between these themes, and those reported in the literature. While there is considerable commonality with issues raised in other studies, the themes in Study 1 produce a broader and more detailed description compared to those reported in other literature. As well, these themes are noticeably different to those used as the basis of methods for evaluating services that are generally in use, although there are developments in the field of service evaluation based on a recovery orientation that are also markedly different to traditional styles of consumer surveys. Two examples are the Recovery Self Assessment (RSA) (Curtis & O'Brien, 2004) and the Recovery Oriented Service Assessment (ROSA) (O'Connell, Tandora, Evans & Davidson, 2002, cited by Department of Mental Health and Addiction, State of Connecticut). In Chapter 9, I

suggested that the difference in the themes that we found conducting Study 1 was due to two features of the research approach adopted: 1. the high level of consumer involvement in the research; and 2. that building a detailed qualitative understanding with data first from focus groups and then interviews allowed me to develop a more fine-grained understanding of consumers' experiences than if I had used focus groups alone. Focus groups alone are, however, the more common approach to item development adopted in other consumer self-rated evaluation surveys described in the literature (Meehan et al, 2002; Eisen et al, 1999; Spear, 2003). The findings from Study 1 support the call for more integrated and complete participation of mental health consumers in evaluation research and highlight a number of important areas relevant to mental health services that consumers' view as needing ongoing attention and improvement.

A number of conclusions about the nature of the experience of becoming a researcher for the mental health consumers who participated can be drawn based on the answers the results from Study 1 and 2 provided to the research questions I posed. Firstly, the experience of becoming a researcher for mental health consumers is similar to experiences of recovery described by others in the literature (Davidson & Strauss, 1992; Deegan, 1988; Ralph, 2000; Ridgway, 2001; Shaheen, Williams, & Dennis, 2003). Secondly, relationships are central to the experience of becoming a researcher. Finally, change is an integral part of the process of becoming a researcher for consumers new to the research field, and this change is due to a number of factors, including: the unknown or unexpected nature of the situation for consumers; the team environment; the new information, skills and knowledge they gain through the experience; and the fundamental features that having a job involves, for example, creating a sense of meaning and purpose

and having a focus in life outside of oneself. The findings from Study 2, with support from Study 1, and the model I have proposed from these findings, have a number of implications regarding consumers' research and work roles, and mental health service provision and rehabilitation programs with a work focus.

### *Implications for Developing Consumers' Roles as Researchers*

One of the broadest implications of my findings is that more research roles need to be available to consumers. The findings from my research also indicate that in developing consumer researcher roles a range of issues need to be considered and addressed. These include: support for consumers in filling researcher roles; training and skill development, so that the expertise consumers bring from their experience is complemented with expertise in research skills and knowledge; and consideration of the limitations of working within mental health services for consumers.

There is already a strong argument evident in the literature that ethically consumer involvement in mental health research is imperative. My research indicates that not only does consumer involvement hold enormous benefit and essential checks to the research process itself (Goodare & Lockwood, 1999; Liberati, 1997) but also that the process of becoming a researcher can be one mechanism consumers' could use to assist their recovery. Indeed, it appears that if the work environment provides adequate training, encouragement and support (contributed to by all team members: consumers and academics), taking on a researcher role in collaboration with academics provides a fertile experimental ground for consumers to elaborate and define their understandings of themselves in relation to others. For the participants in Study 2, becoming a researcher was an experience marked by growing empowerment and personal change, reflected in

the final proposition of the proposed model. This is consistent with other consumer's experiences. Merinda Epstein, now a well-known Australian Consumer Researcher and Activist, wrote in the final report of the *Understanding and Involvement Project*, the project which marked her entry point into the field of mental health research:

It is impossible for me to reflect on my experiences of the 'Understanding and Involvement' Project without alluding to the fact that as much as I have been a witness and contributor to the birth and growth of an ambitious idea (consumer evaluation of acute psychiatric hospital practice!) the project has also been an essential nourishing factor in my own metamorphosis back into worthwhile life. (Wadsworth & Epstein, 1996,<sup>b</sup> p. 193).

Provencher et al (2002) also found, through interviews with consumers, strong evidence that work contributes to the recovery process by providing meaning in consumers' lives.

My findings from Study 1 and Study 2 have indicated that the experience of becoming a researcher involves considerable change and reconstruction, particularly in relation to consumers' meanings about themselves, as the proposed model highlights. Self-reconstruction or transformation is also one of the central themes of recovery. Others in the field have suggested that research evidence provides initial support for the role of work generally as a vehicle of self-transformation in recovery (Provencher et al, 2002). Davidson and Strauss, in 1992, proposed that rediscovery and reconstruction of a sense of self is central to the recovery process for consumers. This position is supported by others in the field, including consumers (Czuchta & Johnson, 1998; Deegan, 1988).

Davidson and Strauss (1992) proposed four basic aspects of the recovery process involving sense of self, which are: (1) discovering the possibility of possessing a more

active sense of self; (2) taking stock of strengths and weaknesses of this self and assessing possibilities for change; (3) putting into action some aspects of the self and integrating the results; and (4) using the enhanced sense of self to provide some degree of refuge from one's illness.

Czuchta and Johnson (1998) have argued that through fostering hope, nurses can assist consumers to engage with the process Davidson and Strauss describe. I contend that by facilitating consumers' fulfillment of roles such as that of researcher, mental health services and the broader community can assist consumers to engage in, and with, these aspects of recovery.

Hope has been identified as closely connected to the rediscovery and reconstruction of a sense of self (Czuchta and Johnson, 1998; Davidson and Strauss, 1992). Miller (1992) described hope as "an anticipation of a future which is good and based upon: mutuality (relationships with others), a sense of personal competence, coping ability, psychological well-being, purpose and meaning in life, as well as a sense of the 'possible'" (p. 414). Miller's definition of hope is concordant with the personal construct view of hope, essentially also about taking the risks involved in engaging with others and anticipating a future (Epting & Amerikaner, 1980). These aspects of hope described by Miller are central to the stories told by consumers in both Study 1 and Study 2, as demonstrated in the themes that emerged from the two studies. Themes in Study 1, as I noted in Chapter 12, appear to be frequently characterised by the relation of unmet need. Themes in Study 2 are markedly different in the sense that more frequently they reflect achievement. It appears that the process of becoming a researcher can be one of hope generation. This process of hope generation is particularly reflected in the themes from

Study 2 of *Broadening personal horizons versus a narrowing world*, *Playing an active role versus not being engaged*, and *Growing empowerment versus power imbalance*.

Change and continuing reconstruction, however, generally are accompanied by emotions of anxiety and uncertainty (Kelly, 1991/1955). Participants in Study 2 spoke about experiencing these feelings at different times while becoming researchers. Most of the CRs spoke about anxiety as characterising their first steps in the experience of becoming a CR, however other vivid examples were also given. As I described in Chapter 12, Susan told me about experiencing anxiety during an interview when the story being relayed by the participant she spoke to was “shocking”. It appears from Susan’s description of this experience that this situation was one to which she had trouble knowing how to respond: her construct system at that time did not adequately assist her to make sense of the situation and guide her behaviour clearly. This was something Susan’s current meanings did not encompass, and she described registering shock, but having an awareness that perhaps she should be behaving in some more facilitative way.

An implication of my findings and proposed model is that both the negative and positive emotions of transition and reconstruction need to be anticipated by consumers when becoming researchers, and by those people supporting consumers during their experience. This includes co-researchers, supervisors, rehabilitation workers, case managers, family and friends – anyone who may be supporting them. Formal lines of support were inbuilt elements of the structure of the Consumer Evaluation of Mental Health Services (CEO-MHS) project team, and CRs employment and roles, which I have described in detail in Chapter 7.

In Chapter 4 I highlighted that experiencing emotions of transition is a feature typical of most career transitions. This is further supported by McCall's (1988) discussion of challenge as fundamental to development in work roles and careers, and description of how people learn and develop new abilities when meeting challenges. McCall suggests that feeling overwhelmed seems to help people develop the ability to adapt. What McCall describes is similar to the experiences participants in Study 2 shared with me.

In the example above, from Susan, the challenge of being shocked, and the anxiety that accompanied facing this situation beyond the range of convenience of her current construct system, clearly precipitated some reconstruction. This is evident in her statement: "I didn't really know what to say to her to defuse the situation, but it wasn't really a situation you could defuse....just me being shocked and sympathising was probably the best thing I could do." It seems that Susan, at the time of conducting the interview she was speaking of, felt anxiety because her constructs around "defusing situations" did not apply. However, her discussion of these experiences with me demonstrates a changed understanding, a reconstruction or perhaps elaboration of meanings about situations, where "defusing" is not applicable, however, where demonstrating shock and sympathy is appropriate.

The model I have proposed, based on the participants' accounts, suggests that the challenge of facing situations consumer researchers find beyond their range of convenience initially coincides with feelings of anxiety, however, that these experiences produce situations in which they then elaborate and change their constructions of their world – and of themselves. It is important that appropriate support is available for

consumers when they face these challenges in their roles as researchers. In the CEO-MHS project, support and supervision were explicitly discussed at a team level regularly, and the active contribution of each team member to creating a supportive and trusting environment was an explicit expectation. The types of support available in the CEO-MHS project included:

- Peer support from other consumer researchers;
- Supervision, one of my central roles;
- Team meetings to address concerns, and training needs; and
- The opportunity to debrief immediately after data collection/interviewing.

Our collective approach to support and supervision was guided by the theoretical concept of dispersed dependency (Kelly, 1955/199; 1969; Walker, 2003). The consideration of formal, inbuilt support and supervision for consumers new to research has been stressed as essential by others writing about collaborative research projects (Allam et al, 2004; Henry et al, 2002; Morrell-Bellai & Boydell; 1994; Ramon, 2001), and my findings support this emphasis. I suggest also that support and supervision is an important, but natural translation of academic and professional training models, and the university research environment, to collaborative research with consumers: as a PhD student and psychologist in training I also received supervision and support from my supervisors.

Collaborative approaches to consumer involvement in mental health research have been strongly advocated by others in the field, drawing on Participatory Action and Action Research approaches (Campbell, 1996, 1997; Danley & Ellison, 1999; Henry et al, 2002; Townsend, Birch, Langley & Langille, 2000; Trivedi & Wykes, 2002). A question worth posing is: *do research roles for consumers need to involve collaboration*



*with non-consumer academics?* The research presented here provides only one demonstration of how consumers' research roles can be developed, and this example grew from a collaborative beginning between the consumer and academic members of the CEO-MHS Management Committee. The consumers involved as CRs in this project were new to research, and so, as anyone new to the area does, needed training in research to complement their expertise gained from using services. This does not, however, suggest that consumers must work with non-consumer academics to achieve in the research field. Consumers with established research backgrounds are in a position to take this role within a research team and there are examples of this occurring, like the User Focused Monitoring initiative in the UK, described by Rose (2001). I argue, however, that the different opportunities in relating that became available to the CRs, through the relationships with me and other non-consumer members of the team, were important in the transition that occurred for them. Working with the academic members of the team provided an opportunity for professional and personal relationships with people outside the mental health system. In addition, in this example, the recognition that the university holds as a research institution provided a different mechanism through which the Consumers' and Consumer Researchers' voices could be heard by others in the community.

Reciprocally, the collaboration that occurred also provided new opportunities for the academic researchers involved in the CEO-MHS project, and additionally, for others within the university environment. Staff not directly involved in the project found the CR team coming and going from their facilities, and the team gradually became a regular part of the work environment. Some CRs continued involvement with other projects within

the Illawarra Institute for Mental Health (iiMH). Over time, the CRs were invited to informal staff activities and celebrations, for example a retirement celebration. I believe this opportunity is just as important as those that opened for the CRs: staff working at a research institute, the iiMH, my base, were provided with a different opportunity for interacting with consumers, and I believe faced situations where they could review their constructs about mental health consumers through these interactions. Exploring their perceptions over this time period would have been an interesting research focus in itself.

It appears that one of the powerful contributing structures that helped create the environment where personal empowerment and growth occurred may be that the team was not situated within the mental health system itself, but in an independent organisation, the university. Roper (2003) writes about the difficulties consumers face working as consultants in the system, and the challenges to being “within”; although she clearly outlines the benefits this position has too. The CEO-MHS research team was however, located outside the system, and it seems this probably has numerous benefits, and could be one very powerful context where consumers are able to become empowered.

Braye and Preston-Shoot (1993) suggest that mental health consumer empowerment “requires a re-framing of the roles traditionally associated with service users and professionals; the negotiation of a different relationship.” (p. 127). They argue that one of the means whereby intentions of services to be oriented toward empowerment of consumers can be turned into reality is by “facilitating access to people outside the professional system” (p. 126). They argue that professionals must recognise the limits of their own ability to help, and the importance of external opportunities and contexts in

achieving empowerment for consumers. The experiences described by CRs in the CEO-MHS team appear to support this claim. It is clear, from participants' reflections during Study 2 that their sense of personal power and confidence did translate from the research environment into the mental health environment. Both San and Ruth gave strong examples of this occurring. It seems likely that participants were able to reconstrue more outside the confines of the mental health system than they had to date within the system. I argue that a different set of opportunities for them to experiment were available in this context, in terms of intellectual activity, and types of relationships. Most importantly, while several CRs expressed feeling some uncertainty during their early engagement with the project about the difference between themselves and the academic team members, the relationships available to the CRs in the team, which initially may have appeared beyond their range of convenience, were free from the traditional connotations that relationships in the service setting carry. There was some power differential experienced, which is apparent in some reports from Study 2, however, I maintain that relationships within the CEO-MHS team were less embedded in consumers' personal histories of power imbalance.

Another important feature of the relationships available in the team related to those between consumers, which were again freed from the expectations and confines of a service setting. Braye and Preston-Shoot (1993) talk about the importance of collective action in empowerment: "the common themes of service users' experiences are what potentially can result in the most effective channels for empowerment." (p. 126). Certainly, CRs reported a sense of collective power.

Kelly (1991/1955) says that people elaborate their construing through interplay with others, through their perceptions of others' perceptions. It is within relationships that people develop, as Walker et al (2000, p. 107) assert:

...the evidence deduced concerning the validity or otherwise of our construing system is overwhelmingly of a social nature. It is embedded in the interactions with others either directly (when we communicate with others), indirectly (when we read or hear what others have deduced from their experimentation), or vicariously (when we observe how others get on with their constructions and experimentation).

Personal construct theory posits that relationships are the context within which people's constructs are tested and then confirmed and disconfirmed to be able to make better sense of themselves. The importance of both confirmation and disconfirmation in construct change is highlighted by Kelly (1966, p. 18) "confirmation may lead to reconstruction quite as much as disconfirmation – perhaps even more. A confirmation gives one an anchorage in some areas of his (*sic*) life, leaving him free to set afoot adventuresome explorations nearby."

The salience of relationships in consumers' work lives generally is highlighted in the literature about experiences of work (Kirsh, 1996; 2000). The evidence of themes about relationships in both Studies 1 and 2, and the theoretical understanding personal construct theory brings to the concept, implies that relationships are another area to which mental health services need to pay close attention: in general service provision, in rehabilitation and work planning, and attainment programs. However, it is also essential that employers, and research teams, working with mental health consumers consider the

importance of genuinely collaborative, participative and supportive relationships. The recovery literature highlights the centrality relationships hold to the recovery process (Repper & Perkins, 2003; Ridgway, 2001; Unzicker, 1989).

For research teams working with and employing consumers, the team will play roles in validating and invalidating consumers' construing: however a strong sense of support and safety within the team is crucial as well, for consumers new to the research field. Consumers spoke particularly about feeling respected and valued as individuals and as a team. This basis of support and safety appears essential for consumers' in navigating the invalidation, and the need to change (that is, experiencing anxiety which indicates that the situation they are facing is beyond their range of convenience) that occurs as part of doing the job of researcher. Involvement in research teams can be one pathway to achieving inclusion, or of being "let in" to a sense of community (Davidson, Stayner et al, 2001).

*Provision and Practice in Mental Health Services: Clinical Implications of the Findings from Study 1 and Study 2*

Currently, Mental Health Services internationally describe a recovery orientation as fundamental to their service approach (Australian Health Ministers, 2003; Department of Health, 2001, 2003; Jacobson & Curtis, 2000; President's New Freedom Commission on Mental Health, 2003; US Department of Health and Human Services, 1999). My research indicates that for services to achieve a recovery vision more attention needs to be given to facilitating opportunities for consumers to fill researcher roles. Additionally, opportunities for consumers to genuinely impact on research agendas need to be established. These opportunities need to begin within services themselves, with their own

research policies and practices. Mental health services should also become more active in advocating for consumers' roles in research with other organisations.

The features participants spoke of in my research as important in their experiences of becoming researchers (ie: supportive relationships, valuing of individuals, having a meaningful occupation and being paid) need to be available in a multitude of settings, a contention supported by Repper and Perkins (2003). An implication of the research presented here is that mental health services need to pay greater attention to these aspects of consumers' lives generally if they are to genuinely assist consumers' recovery. The recovery and work/rehabilitation literature further supports the concept that researcher roles are not the only roles in which consumers experience the necessary supports for actively engaging their recovery journey. In fact, there is an abundance of literature demonstrating that they are not: however a *meaningful* work role is highlighted as particularly important to consumers in much of the recovery literature (Shaheen et al, 2003).

The centrality of relationships to consumers' experiences, in my findings, indicates that opportunities for employment and relationship development, beyond the service environment need to be available to consumers. These opportunities include general employment, as well as employment and training specifically as researchers. Organisations, such as peak bodies and universities, are examples of organisations in which opportunities can be sought and facilitated by services and consumers, for consumer researcher roles to be developed. Given the fundamental component relationships played in CRs experiences, and the importance placed on relationships by consumers in Study 1, services should also be helping consumers to connect with other

opportunities in which meaningful relationship development can occur outside of the service setting: for example, by supporting consumers to engage with their local community and recreational groups. This recommendation is supported by Davidson, et al's (Davidson, Haglund et al 2001; Davidson, Stayner et al, 2001) findings regarding consumers' experiences of a supported socialisation program. The Partnership Project, reported by Davidson, Haglund et al (2001), is one clear example of how services can facilitate meaningful relationship development with consumers. Anti-stigma campaigns and community education about mental health and illness are important steps mental health services need to be taking, to develop these opportunities for consumers to engage in meaningful relationships with people outside the system. My findings from Study 1 and Study 2 demonstrate the currency of stigma as a major barrier which consumers' experience.

I have already shown how my research holds implications for the broader area of rehabilitation and work programs in mental health. Sane Australia, in their Blueprint for Employment and Psychiatric Disability (2003<sup>a</sup>) analysed the cost of not providing comprehensive employment support to consumers. They argue that on economic grounds alone, "there is a substantial incentive for government to provide improved mental health services, and, in particular, employment support for people with a psychiatric disability...-quite apart from the health and quality-of-life outcomes for consumers and carers." (p. 33). I strongly emphasise this observation.

Commonly held perceptions within the mental health field and the broader community about consumers' abilities to work have impacted on opportunities for consumers to fill work roles (Boardman et al, 2003; Harnois & Gabriel, 2000; Sane

Australia, 2003; Schneider, 1998). My research provides further evidence against the commonly held perception that “people with psychiatric disabilities cannot tolerate stress on the job” identified by the WHO as one of the major myths about work and mental illness (Harnois & Gabriel, 2000, p. 29). Clearly, from the participants’ stories, they experienced high job stress at various stages throughout their work as CRs, and there is clear description by them of both positive and negative emotional experiences throughout the journey. Within the context of a work situation that offers consumers an appropriately supportive and flexible work environment, as well as supportive and accepting open relationships, it is clear that consumers can withstand stress in their work lives.

Traditionally, vocational rehabilitation approaches in the mental health field have relied heavily on pre-employment testing, counseling, and skills training (Drake, Becker, Clark & Mueser, 1999; Grove, 1999; Quimby, Drake & Becker, 2001). These traditional approaches to vocational rehabilitation have been extensively criticised for this focus, doing little to assist consumers to achieve real employment (Crowther, Marshall, Bond & Huxley, 2001; Mechanic, 2003; Quimby et al, 2001). Additionally, criticism has been directed towards the tradition of focusing efforts within a disability perspective, which has resulted in mental health services facilitating consumers work roles within sheltered employment settings (Hardy, 1993; Sane Australia, 2003; Young, 2001).

There is clear evidence, despite the traditional focus of vocational rehabilitation, that a significant number of consumers prefer open-employment over other types of employment (Grove, 1999), and that finding competitive work should be a goal for mental health services (Eklund, Hansson and Ahlquist’s, 2004). Supported employment approaches directly promote consumers’ fulfillment of competitive, open-employment



roles, with ongoing support and training received on the job (Bond et al, 2001; Drake et al, 1999). Sane Australia, however, defines a supported employment model differently to the US definitions, referred to above, indicating difference in Australian understandings of what supported employment means. The Consumer Researcher roles in the CEO-MHS project are an example of real life, open employment of consumers, with careful consideration of appropriate and individualised support on the job, and so could be described as similar to a supported employment model, similar to those in the US.

Research work in any field typically allows for multiple employment options: research is an employment area that readily lends itself to part-time or casual work, as well as full-time positions. Additionally, research is frequently conducted in a team environment, which may be particularly helpful for consumers in employment. Research work also provides diversity, and choice over tasks and activities conducted (Henry et al, 2002). For these reasons, the research field generally could be particularly suitable as an open-employment area ripe for consumer involvement. Additionally, mental health research specifically contributes further to the possibilities it opens for consumers: consumers' bring unique knowledge and perspectives to an understanding of mental health and mental health services.

Barton (1999) indicates the equivocal nature of findings from different studies of supported employment. While some investigators consider their findings evidence that direct job-placement is the most effective approach for employment services to adopt in the mental health field, other findings indicate that approaches that integrate mental health services with vocational services, in the form of skills training and day treatment with a vocational focus produce better results (Barton, 1999).

Grove argues further, that: “Rehabilitation services that restore work-related skills and that help individuals develop a new self-image as workers, not just as mental health consumers ...are necessary.” (1999, p. 11). A range of problems have been identified with rehabilitation programs that emphasise skills development as a prerequisite for seeking and finding work (Shaheen et al, 2003) and Grove suggests that building appropriate skills for success in the work setting is a preferable alternative. My findings indicate that on-the-job research skills training of consumers was successful in our experience.

My findings also clearly demonstrate that the mental health research field is an important area in which roles of consumers need to be given more attention by consumers, researchers, and mental health professionals. The qualitative findings presented here indicate that this field is one in which consumers can enter the open-workforce, and skills training can occur in a context related to their roles. The CEO-MHS project demonstrates how skills development in the context of work can successfully occur in the research context. Additionally, skills development, while working in the field is consistent with the development of most researchers. Again, I argue that the research setting provides a highly suitable work opportunity for on-the-job training of consumers. The results from Study 2 demonstrate the personal success CRs perceived in being involved in the CEO-MHS project, while the outputs of the project itself (the questionnaire and Evaluation Framework developed, as well as conference presentations and reports) demonstrate the success of the project more broadly.

*Theoretical and Methodological Implications of the Findings from Study 1 and Study 2*

I argued in Chapter 3 that alternative theories to the medical model are necessary to underpin collaborative research with consumers of mental health services, given that the medical model has established a tradition of discounting consumers' views (Shanley et al, 2003). A further implication of the research I have presented is that personal construct approaches to understanding consumers' experiences appear to be highly useful. Adopting personal construct theory has enabled me to maintain a focus on the data, the accounts of those consumers from Study 1 who enabled me to understand what it means to use mental health services, and the stories of consumers experiencing the transition to researcher in Study 2. However, at the same time, personal construct theory provided me with one of the lenses through which I can understand these consumers' experiences, and produce an interpretation markedly different to one that would be proffered through a medical model lens.

The research I have conducted also importantly contributes to the growing body of evidence demonstrating the usefulness of phenomenological, consumer-directed and participatory approaches to research, and most specifically, of IPA (Smith et al, 1997; Smith et al, 1999; Willig, 2001) as a tool that assists in conducting this style of research. Both Study 1 and Study 2 reaffirm many themes evident in the literature describing consumers' experiences of using mental health services, and of recovery, such as: the impact of stigma, the effects of feeling powerless and/or a sense of power, and the importance of relationships with a range of key others, including staff, family and friends. The resonance with earlier findings is validation of the usefulness of IPA, and the broader research approach I have taken.

A final, important implication of the research I have presented here also relates to method. Cohen, Duberley, and Mallon (2004) note that in the career development and change literature, there have recently been calls for adoption of narrative approaches to understanding career, thus gaining a more wholistic view of career. These authors argue that “generation of narrative accounts is a powerful – and appealing – method” (p. 411) in contrast to the tendency they note towards positivistic approaches to career research that has dominated the field. Methodologically, this study offers a further example of the utility of understanding career experiences – one frame through which this study may be viewed – using qualitative, narrative type approaches. Using a range of qualitative data collection methods, several directly informed by personal construct theory, and adopting interpretative phenomenological analysis, I have developed an in-depth description and understanding of the experiences of these consumers’ career development: becoming researchers.

#### Limitations

One of the most important limitations of this study is the retrospective nature of the data collection carried out with Consumer Researchers: they were asked to reflect on their experiences close to the end of their work as CRs on the CEO-MHS Project. From the personal construct perspective, this means I would have accessed Consumer Researchers meanings about their experiences at that time, which would likely be different to their meanings held at earlier points in their experience as CRs. This is particularly relevant given the clear reconstruction that occurred for participants.

Smith (1994) explored the nature of transition to motherhood qualitatively with four women. He compared the women’s real time and retrospective data to understand

what differences occur between contemporaneous and retrospective collection of this type of data. Smith describes reconstruction of the experience as evident in the women's accounts of pregnancy, after their child was born. For example, some of the women's retrospective accounts show instances of a positive gloss on the more difficult experiences described during their pregnancies. Additionally, Smith (1994) suggests the women's stories at other times exaggerate the negative views and points from the past, and at times Smith found the women to hold two conflicting stories at the same time. Adding to the impact of this limitation, some CRs had difficulty remembering clearly earlier periods of their experience as CRs, and said so in interviews. As Smith (1997) indicates, a dynamic view of the person, and that underlying personal construct theory and this research, is consistent with a reconstructive model of memory. As Osborne and Coyle (2002) argue, also, it should not be assumed that autobiographical memory and retrospective accounts are necessarily inaccurate.

The focus and aim of this research study, however, developed and was defined as the CEO-MHS project itself progressed. Originally, my research focus was on understanding and developing the model of consumer evaluation of mental health services in partnership with the participants and CRs. As we collaborated, however, two issues became apparent: first, that it was not appropriate for me to produce a model of consumer evaluation of mental health services, rather, this needed to be one of the products of the entire team; and second, that the experiences of the CRs were a rich and valuable source of information that as yet, our team was not capturing. While, as a team, we had some sense that someone should be researching the researchers' experiences, we were busy conducting the research that was our main focus. Gradually, together, we

began to articulate the need for this component of the teams' experiences to be explored, and so the research presented here began to be defined. This emergent and evolutionary nature of research definition is a common feature of qualitative studies.

Understanding this limitation from a personal construct perspective, the meanings CRs give to their experiences at any point in time are as valid and important as those given at any other point in time. This perspective posits that I could only achieve an understanding of CRs construing at whichever particular time data was collected: Kelly (1991/1955) suggests we are selves in motion, regularly constructing and reconstructing. Future research with consumer researchers should seek consumers' meanings earlier in their research experience, and ideally, repeatedly over the course of their involvement in a research project. This would add important detail to the model I have developed, and provide further rich evidence about the experience of becoming a researcher. Similar methods adopted in this study could be used, and additionally, I believe further research could effectively make use of diary recording by consumers.

Another important parameter within which this research needs to be understood is that qualitative research generally makes no "claim of the generalisability of findings to a specified larger population in a probabilistic sense" (Fossey et al, 2002, p.730). Qualitative researchers tend to distinguish between statistical or empirical generalisation, and theoretical, or logical generalisation (Sim, 1998; Woolgar 1996). This second type of generalisation refers to an attempt to make theoretical or conceptual insights based on qualitative data, which can be tentatively projected to other contexts and/or situations (Sim, 1998). This is the type of generalization I have attempted, by producing sets of themes from both studies, and developing a model of the experience for consumers of

becoming evaluation researchers. Caution is needed in making generalisations from the findings reported here to the broader mental health area. My findings, and the model I proposed, need further validation and testing now, for their applicability and utility in other contexts to be better understood. It has been developed based on data from a group of consumers from one geographical locality, employed as researchers on the same project. The CEO-MHS project they worked on had a focus located within the mental health field, involved collaboration with academic researchers and graduate students, and employed a large team of consumer researchers together. Further studies with other groups of consumers becoming researchers need to occur, to see if the model is applicable to broader research contexts, approaches and projects. The model now needs validation and refinement.

This limitation is common to models developed from qualitative research, reflected in Harre's words (1979, cited in Smith, 1997, p. 193):

I would want to argue for a social science...which bases itself upon an essentially intensive design, and which works from an idiographic basis. Nevertheless such a science is aimed always at a cautious climb up the ladder of generality, seeking for universal structures but reaching them only by a painful, step by step approach.

These models, however, are reflective of the rich and complex situations people face, and it is for this detailed and rich understanding that qualitative approaches are chosen.

A third important consideration, necessary to understanding the research I have presented here, relates to my multiple roles in this research and my multiple relationships with CRs who were participants of Study 2. I was at times research trainer and mentor,

supervisor, colleague, and ‘researcher’ in relation to the CRs in Study 2, and additionally, I believe, friend and personal support to some of them. This undoubtedly impacted on the data I collected in the focus group and individual interviews with CRs. This could be particularly problematic because I also acted to interpret the data collected, and my multiple roles must be remembered when this analysis is read. I did, however, make a number of attempts to ensure that the interpretation I developed was an authentic representation, by providing participants with my interpretations, and directly asking for feedback about how well this fit with their experiences. This limitation is not as salient in terms of the interpretation of Study 1 data, because firstly my relationship with participants in this Study was more linear in nature when I met these participants, and secondly CRs were also involved directly in analysis of that data.

In addition to my attempts to ensure my interpretation was an authentic representation, judged by CRs themselves, the method of analysis I used, IPA, I chose specifically because it integrally acknowledges the interpretative nature of data analysis. Central to IPA is an understanding that the interpretation arrived at is my interpretation, inevitably arrived at through my personal meanings (Smith et al, 1999). The challenge of representation is one other authors have also discussed (Thompson, 2001), and Thompson suggests that it must be acknowledged that an interpretation only reflects the author’s understanding of their participants accounts, however, that interpreters should be aware of distancing and separating researcher and researched, objectifying what is being studied.

A final limitation of the research I have presented relates to the multiple interviewers who conducted data collection with consumers in Study 1. Often, having



multiple interviewers conduct a single piece of research is seen as reducing consistency and reliability of the research conducted (Patton, 1990). In this research, however, a number of other issues were also particularly salient, including:

- a) addressing the power imbalance inherent in asking consumers to discuss their experiences of using mental health services with established ‘academic researchers’ and responding appropriately to the evidence that consumers prefer to discuss these type of issues with other consumers, and in fact, that importantly different information is received if consumers act as interviewers in this situation; and
- b) the underpinning belief within the CEO-MHS management committee that employing a relatively large group of consumer researchers would be most appropriate to conduct this type of collaborative research project because, a larger team: allowed for greater flexibility and choice of work; and produced a larger network of support and commonality (based on spread of dependency).

To address issues of consistency, CRs took part in training sessions together, in which interview technique was discussed and explored, and CRs had opportunities to role play interviews. A semi-structured method for interviewing was adopted, which as Patton (1990) describes, is particularly useful in establishing a level of standardisation and consistency when multiple interviewers conduct the data collection. To support the interviewing, as I described in Chapter 10 an interview guide was used by all CRs, and was utilized in their training and practice sessions. I believe that while the effect of multiple interviewers must be acknowledged and considered in viewing the results from Study 1, this limitation is counterbalanced by the purpose of these interviews and the nature of the research question guiding the study. Using multiple interviewers was

consistent with the overall methodology of conducting semi-structured interviews, and of engaging in participatory and collaborative research.

### Assessing the Results Against Criteria of Good Qualitative Research

In Chapter 6, I presented a range of criteria for determining the quality of qualitative research. I will now use the set of strategic suggestions related to achieving authenticity, provided by Manning (1997), to review the research I have conducted. As I stated in Chapter 6, Manning is clear that the set of choices she proposes should not be viewed as a checklist to be applied in a prescriptive manner, and in this analysis I will therefore, not be attempting to demonstrate that I have exhaustively applied Manning's set of suggestions, but will use these as a guide to consider how authenticity has been achieved in my research.

Manning (1997) indicates that one type of authenticity in constructivist research is fairness, which relates to achieving a balanced interpretation, reflecting the range of views expressed by participants. To ensure participants' voices, and lived experience were clearly represented, I relied strongly on quotations from the transcripts throughout both studies, to present the results. Additionally, these quotes have come from many participants, rather than relying on only one or a few participants voices through which to present my interpretation.

Participants in both studies were involved in checking and contributing to the interpretation of their data, and the analyses I have presented reflect a synthesis of multiple perspectives. In Study 1, I conducted analysis of focus groups personally, and several team members then checked the transcripts and my interpretation, adding to the final understanding of the stories we were told. Separate analyses of the interview data

from Study 1 were conducted by myself and one CR from the team (based on three quarters of transcripts), who had been trained in the analysis method and in using NVivo. Once we had developed our own interpretations of the interview data, we worked together to produce a collective understanding, which we shared with the CEO-MHS team, and with participants from interviews in feedback sessions. The other important aspect of the research design which impacts on achieving fairness is the sampling approach I adopted for the interview stage. The purposive sampling approach used ensured that participants with diverse experiences of mental health services stories were heard, to produce a rich and broad understanding of what it is like to be a consumer of public mental health services.

My analysis of data from Study 2 was shared with CRs at two stages. Initially, I provided CRs with a draft outline of the themes and discussed these with them at an early stage of my developing my interpretation. Once I had produced the written version, presented here in Chapter 11, each participant was provided with a printed copy of the chapter and asked to comment, particularly paying attention to the way I represented them personally. Feedback about Study 1 and Study 2 from participants was that participants found the interpretation meaningfully captured their situations and experiences. Additionally, other consumers commented on how closely they could relate to the themes when these results were presented at conferences. My final point relating to fairness is that I have explicitly attempted to demonstrate in this report my own perspectives and theoretical influences.

Manning (1997) also discusses authenticity relating to issues of whether the research process improves participants' understanding and experiencing of their world -

ontological authenticity; and of others - educational authenticity. My understanding of personal construct theory, and the interconnection of the personal and social in forming people's meaning systems, as I described in Chapter 3, leads me to consider these forms of authenticity together. The approaches adopted to data collection in Study 1 and Study 2 were semi-structured to ensure that participants had an opportunity to impact on the nature of the discussions that took place. While my relationship with CRs could be viewed as a limitation to the objectivity of data collection from some more positivist perspectives, I believe our relationship, which had developed over two to three years of working together, allowed alongside careful use of semi-structured techniques, for a genuine dialogue, or what Manning calls "dialogical conversation" rather than one way data gathering efforts. Using the "Let's Just Say" method, the Experience Cycle methodology and inviting CRs to complete self characterisations assisted participants and I to collaboratively explore their meanings relating to their research experience. CRs conducted the focus groups and interviews in Study 1, to ensure that participants felt safe and respected, acknowledging the power imbalances described previously by consumers in relation to participation in traditional research. The nature of the data collection in Study 1 allowed consumers to meet and talk, which clearly for the CRs involved, built further their understanding of others diagnosed with a mental illness and of the consumer movement more generally. I expect that this may have been reciprocal for at least some of the participants in Study 1. Sharing of results in feedback forums, and reflection on these by participants in these forums also allowed participants the opportunity to learn about the collective experiences of the consumers we spoke to in Study 1, in addition to being able to check and have further input into the interpretations my colleagues and I

had made of the data. Similarly, I held discussions of my analysis and interpretations, and provided an opportunity to review of a draft of the results chapter (Chapter 11) with participants in Study 2. Finally, in relation to these forms of authenticity, the descriptive model I have developed of the psychological experiences of becoming a consumer researcher captures the common patterns of the experiences described by participants, and can be easily conveyed to other consumers, researchers, clinicians and service managers interested in better understanding consumers' roles in research.

Manning (1997) also suggests that the question of who owns data is central to the issues of ontological and educational authenticity. I chose Interpretative Phenomenological Analysis as my method of data analysis specifically because this method of analysis recognises the interpretative role and the limitations of this, while the method focuses clearly on attempting to understand participants' meanings. The research I have conducted, described here, is essentially of a collaborative nature, and so interpretation was a shared effort, as I have already described. In Study 1 this meant that CRs worked on interpreting interview data and a joint analysis was then shared with participants for discussion and validation. In Study 2, the collaborative approach I used meant that I shared and discussed my interpretations with CRs as described in Chapter 10.

The collaborative nature of the entire research endeavor also relates closely to the fifth type of authenticity elaborated by Manning (1997), tactical authenticity. Manning suggests that approaches to research that involve co-researcher relationships with participants, rather than researcher/object relationships provide opportunities for empowerment, rather than abuse of power.

### Suggestions for Future Research

After considering the research and its limitations in the above sections, I conclude that future research could be conducted specifically to:

1. Address the retrospective nature of the data collection in this study. I suggested above that interview methods, or diary recording could be particularly helpful earlier in consumers' experiences of entering the research field to avoid the possible limitations of working only with retrospective data. Additionally, longitudinal data collection could also be revealing, to develop a more greatly defined/refined model of the experience of becoming a consumer researcher.
2. Validate and refine the model for mental health consumer researchers I have presented. I suggested that it will be particularly important now to test this model with other mental health consumers new to research, embarking on the transition to researcher. Future research might also examine the usefulness of this model with other populations new to research.
3. Given the growing emphasis in all areas of health policy for consumer involvement in research, the findings from my research could usefully in future, also be applied and tested in other health areas, with consumers of general health services new to research.

Another area in which I consider future research may be directed relates to developing clear guidelines and approaches for mental health services and affiliated organisations to fully involve consumers in mental health research. As well future research could explore more closely the links between the experience of becoming a researcher and recovery for consumers.

In discussing the implications of the findings from Study 2, I reflected on how the CR team became part of the university environment, and may have forced some staff to develop new meanings about mental health consumers. I suggest that future research where consumers work within a university environment, or another environment outside of mental health services, could usefully focus on what effect this type of interaction with consumers has on other's understandings of people with mental illness. I believe this may provide important information about how to change and challenge community perceptions of mental illness, and people with a diagnosis.

### Conclusions

Very little research exploring the experience for consumers in fulfilling research roles has been conducted, despite the emerging push to involve consumers more fully in research in the mental health field. I have presented two studies that have explored the experiences of consumers, their experiences with mental health services and becoming researchers. My aim was to use accounts by consumers of mental health services to develop a model of the experiential and psychological processes of consumers in becoming researchers. I posed five Research Questions, the first of which explicitly directed attention to understanding the experiences of consumers using mental health services, while the following four questions directed attention to focus more specifically on consumers' experiences becoming researchers, and the transition this involved. Addressing these research questions lead me to developing the model, of mental health consumers becoming evaluation researchers, from consumers' accounts, and supported by personal construct theory.

The findings I have presented here describe the experiences of consumers taking on the work role of researcher, an area to date little explored. These findings are significant because they explore the impact, from a consumer perspective, of a new pathway to open-employment for consumers and the mental health services supporting them. These results are also significant in the contribution they make to the understanding of recovery, and approaches to supporting recovery. It is unlikely that one approach to facilitating consumer participation and employment will, on its own, bring about broad and lasting changes to the mental health field. This research is significant in challenging some traditional perceptions of consumers', and by adding to knowledge about different choices for services research, ways to facilitate recovery, and employment.



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## APPENDIX A

### EXAMPLE INFORMATION AND CONSENT FORMS

## UNIVERSITY OF WOLLONGONG

Information Sheet**CONSUMER EVALUATION OF MENTAL HEALTH SERVICES:  
THE EXPERIENCE OF BECOMING A CONSUMER RESEARCHER**

You know all about our CEO-MHS project, and our overall aims for the project to:

1. develop an evaluation framework, which provides a way to evaluate MHS from a consumer perspective; and
2. develop questionnaires/tools as part of this framework, asking questions about services that are relevant to consumers.

You are a vital part of this team, and **as you're probably aware, some of the things we are doing as a team are quite new** to research. The role you play, as a consumer becoming a consumer researcher, is one important aspect that is quite new.

*As part of my PhD research, I'd like to find out more about this aspect of our project because I think it's an area that we all need to know more about. I also believe that other people – consumers and academics alike – need as much information about what it's like for you, to help more consumers become researchers in the future.*

**To do this, I need your help.** *I would like to invite you to take part in this research project, as co-researchers. Your job will be to help me understand what it's like to be a consumer becoming a researcher – what working on this project has been like for you. My job will be to make sense of the information you give me, trying to understand what it's been like for you, and to put all the stories from CRs in the project together into a joint story. I will be doing this to help both us as a team, and other people, understand more about what it's like to be a consumer becoming a researcher. I am asking you to work with me until, together, we are happy with the understanding we develop.*

Specifically, what I'll be asking you to do will include:

- mapping personal experiences that have been critical to your experience as a CR;
- writing about yourself as you were just before joining the project;
- writing about yourself as you are now;
- taking part in a focus group – reflecting on the themes from CEO-MHS interviews and their relevance to your experience as a CR;
- taking part in two interviews – where I'll be asking about your experiences and asking you to reflect on some of the writing and mapping you've done;
- giving me feedback on my attempts to understand your experiences.

**Choosing to participate in the research is voluntary.** You are free to refuse to participate, or if you choose to participate you may withdraw consent at any time.  
**Participating, refusing consent, or withdrawing consent will in no way effect your employment as a Consumer Researcher on the project. .**

Any information you give during participation will remain confidential. To ensure this, I will use numbers to identify data rather than names, and in reporting about the project your name will not be identified. Instead, I will ask you to choose a pseudonym for me to use when I write about your experiences.

**I will not discuss information you give to me with other members of the team, without your consent, except in supervision with Lindsay and Linda. I will not discuss information you provide participating in this project with IAHS or people outside the research team.**

If you choose to participate, data collected will be used as part of my thesis, as well as journal articles and conference papers/presentations.

If you have any questions about the research and your participation, please ask the researcher with you or contact:

Gillian Malins           (02) 4221 4164, or  
Dr Lindsay Oades       (02) 4221 3694 (Supervisor)

If you have any concerns, queries or complaints regarding the way in which the research is or has been conducted you should also contact the Secretary at the University of Wollongong Human Research Ethics Committee on (02) 42214457.



**UNIVERSITY OF WOLLONGONG****Consent Form****CONSUMER EVALUATION OF MENTAL HEALTH SERVICES:  
THE EXPERIENCE OF BECOMING A CONSUMER RESEARCHER**

I have been given information about "Consumer Evaluation of Mental Health Services: The experience of becoming a Consumer Researcher " and discussed the project with Gillian Malins who is conducting this research as part of a project funded by the Australian Research Council, the University of Wollongong, and the Illawarra Area Health Service.

I understand that this research is being conducted by Gillian as part of a PhD supervised by Associate Professor Linda Viney and Dr Lindsay Oades in the department of Psychology at the University of Wollongong.

I have had the opportunity to ask Gillian any questions I have about the research and my participation.

I understand that my participation in this research is voluntary. I am free to refuse to participate, and I am free to withdraw from the research at any time. My refusal to participate or withdrawal of consent will not affect my employment in any way.

The information sheet I have been given has details about contacting Gillian Malins and Dr Lindsay Oades if I have any concerns or complaints regarding the research or the way it is/has been conducted.

By signing below I am indicating my consent to participate in the research "Consumer Evaluation of Mental Health Services: The experience of becoming a Consumer Researcher." I understand that data collected from my participation will be used for a thesis, journal publications and conference publications.

---

(Please sign

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/ /  
(Date)

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(Please print

## APPENDIX B

### INTERVIEW GUIDE FOR STUDY 1

<b>CEO-MHS INTERVIEW GUIDE</b>
--------------------------------

**WHEN THE PARTICIPANT ARRIVES:**

- Introduce yourself – explain who you are
- Show participant where facilities are – toilet, tea/coffee etc.
- CHECK IF THEY RECEIVED INFORMATION SHEET

All participants should have received an information sheet before they came to the interview. If they didn't:

- you have spare copies – give them one of these
- let the participant take the time they need to read through this
- if any participant says they didn't/couldn't read the information sheet, you need to outline what it says.

The information sheet says:

*- the project – Consumer Evaluation of Mental Health Services:*

*Developing an evaluation tool in partnership with consumers – is funded by the Australian Research Council, the Illawarra Area Health Service, and the University of Wollongong.*

*- A team is working on the research – this includes researchers who are also mental health consumers, and researchers from the Uni.*

*- The research is also part of a PhD being conducted by Gillian Malins*

*- Participating will involve taking part in an interview*

*- We will ask about their experiences of mental health services,*

*What has been good*

*What has been bad*

*What they would ideally like in a service*

- *We are very interested to hear what they have to say.*
- *Will take about an hour*
- *Researcher who has had experience using a mental health service will conduct the interview*
- *Interviews will be taped (audiotape) & transcribed (typed out).*
- *Anything they tell us will remain confidential.*
- *They are volunteers – they don't have to participate*

*They can stop the interview at any time if they want and not continue*

*If they do this, it will not affect their treatment with the IAHS in any way.*

*They can contact members of the team – our numbers are on the form.*

- ASK IF THEY HAVE ANY QUESTIONS ABOUT THE PROJECT, THE INFORMATION THEY RECEIVED, OR THE INTERVIEW.

If you aren't able to answer any questions they have:

- let them know they can contact either Gillian Malins or Kim Morland to find out more. Our numbers are on the information sheets.
  - ask them if they are willing to do the interview today anyway
- ASK THEM TO FILL IN THE CONSENT FORM, when they are ready to begin.

If they don't want to fill in consent form:

- Explain that the form says they have been given information about the project and that they agree to take part in the interview
- Explain that you are not able to do the interview without informed consent

If a participant still does not want to continue – let them know that you are sorry, but you won't be able to continue with the interview. Thank them very much for their time, and for coming and finding out more today.

▪ ASK THEM TO FILL IN DEMOGRAPHIC SURVEY.

When you ask them to fill this survey in, you will need to explain that:

- usually when you do research, you give an explanation about who took part – for example usually you will write details to explain what sort of age group participants were in, how many males and females took part.
- we won't keep any identifying information with this form – we won't know who's details they are (ie: their name won't be on it, or kept with it)
- Nothing personally identifying will be written about them (we won't use their names, or give detailed information about them that will allow people to identify them by reading our reports)
- they don't have to fill the form in, however other people (Mental health services & other researchers) will take more notice of what we have to say if we can explain where our information has come from.

- When all forms have been filled out, put them into the manilla envelope you have – this helps ensure confidentiality.
  
- When you are both ready to start – let the participant know you are ready to start the interview. REMIND THEM:
  - The interview is being taped
  - When the tape is transcribed (typed out) we won't include their name
  - If at any time they decide they don't want to continue you would like them to let you know – they can leave any time they want
  - Ask them to let you know if they need a short break.
  - 
  - For some people the interview process may be too long without taking a short break between questions.
  
- Let them know you might take some notes during the interview – just to help you remember what they have said etc.
  - Reassure them that this is just for your own benefit – to help you conduct the interview & not forget anything you want to go back to , or anything you need to do.

Turn on the tape recorder – make sure you press record on the deck, and put the microphone to 'on'.

---

**If you are not sure that the tape is recording properly – it is OK to check this first with your participant. Just let them know you want to check that it is recording properly. Say something fairly brief with the recorder taping, then play it back to hear if it has taped.**

## **THE INTERVIEW**

Some things to remember:

It is important that you let the participant respond very freely to the first 2 questions. YOU CANNOT GUIDE THEM. However, you can use probes to find out more. Remember – ask things like: “Can you tell me more about...”

<p><b>Q1. Can you tell me about your experience of the Mental Health Services that have been provided for you, the good and the bad?</b></p>
--

Prompts/ Probes: use these to get more information once the participant has answered you...

- What do you think about the quality of care you usually receive from health professionals?
- What about the quality of the different types of services such as the crisis team, in-patient, out-patient or other services you have received?

**Q2. If you could have an ideal service, what would it be like?**

The next 6 questions are asking the participant to focus on some more specific areas.

YOU ONLY NEED TO ASK THESE QUESTIONS IF YOU FEEL THE PARTICIPANT HAS NOT COVERED THESE AREAS IN THEIR ANSWERS ALREADY, OR IF YOU FEEL THAT ALTHOUGH THEY MENTIONED THE AREAS, THEY DID NOT TELL YOU MUCH.

- If you aren't sure – ask the question anyway.
- If they have already mentioned one of these areas, but you want to ask them some more...change the question to reflect that you heard them bring this up already, but you want to know some more.

For example

The first question could change to:

You mentioned feeling isolated earlier. Can you tell me some more about this?

THE PROMPTS ARE THERE TO HELP YOU GET INFORMATION – AGAIN, YOU ONLY NEED TO USE THEM IF THESE ARE THINGS THE PARTICIPANT HAS NOT TOUCHED ON.

REMEMBER – EACH INTERVIEW WILL BE A BIT DIFFERENT DEPENDING ON WHAT THE PARTICIPANT SAYS.



**Now I would like to ask you about some things that other people have said to see if these have or have not been important for you.**

**Q3. Some people have said isolation and a lack of community involvement was an issue for them. Has this been important for you?**

- What about negative perceptions or stigma?
- Do you feel people have isolated you because of your mental illness?
- What would alleviate your isolation? (only ask if the person states they feel isolated)
- Do you think others don't understand what it is like to have a mental illness?

**Q4. Some people have felt like they haven't had control over some aspects of their life due to their mental illness, have you had experiences of feeling like you had no power?**

- Can you tell me about times and situations when you felt either powerful or powerless?
- Has this been an issue with health professionals?
- What are your thoughts about how much control you have over your life when you are unwell?

- At these times do you think the balance of power between you and health professionals is appropriate to your situation?
- How do you cope with having a mental illness, both when you are functioning well and when you are in crisis?

**Q5. Stigma is another issue for people who experience mental illness. People can feel devalued by other people as a result. Have you had any of these experiences?**

**If so, where and with who have you experienced this and what was it like?**

- What about when you were unwell and receiving treatment?
- Do you think this situation is changing?

**Q6. Many people spoke about their good and bad experiences with medication. Can you tell me about your experiences with medication?**

- Do the negative side-effects of many of the current medications worry you?
- Can you tell me about how your medication helps you to cope with your mental illness?
- Do you have enough information about your medication and its side effects?

**Q7. Can you tell me how you feel or what you think about consumer involvement in the provision of mental health services?**

**(eg: as consumer reps, consumer rehab assistants etc)**

- Is it important for you to have consumers involved in the provision of mental health services? If yes, what is it about consumer involvement that is important or unique?
- Can you tell me about any consumer involvement that has been important for you?

**Q8. Receiving information and education about their particular mental illness and treatment has been important for some people. Has this been important for you?**

- What would be the best way for you or others to receive this information?
- If this isn't or hasn't happened what do you think stops this?
- Do you think the general community (including those with mental illness) are adequately informed about mental illness? If not, what do you think ought to be done to better inform or educate people (including police, ambulance officers)?
- What do you think are the most important things for mental health staff to be educated about?

### **ENDING THE INTERVIEW**

- Let the participant know you have finished asking them questions/ you have covered everything you need to in the interview.
- Check if they have anything more they want to say.
- When they are finished, **turn the tape recorder off. Make sure the microphone is switched back to 'off'**
- Thank them for participating
- Let them know you enjoyed talking to them
- Also let them know that their contribution is very important to us. This research couldn't be happening without them.
- Ask them if there is anything they want to ask, or discuss before they leave.
  - If they have a lot of things to discuss, you might need to:
    - Encourage them to phone either Kim Morland or Gillian Malins to discuss these things if they are about the project;
    - Encourage them to speak with their family/ friends/ support worker etc, if they have a lot of things they want to discuss about themselves/ their treatment etc.

- Make some conversation with the participant before they leave.

This is important to help them ‘switch off’ from the interview, and go back into their normal day.

You might ask them

- What are you doing this afternoon?/ Have you got plans for the rest of the day?
- What have you got planned for the weekend? / What are you doing this weekend? - (if it’s late in the week).
- How was your weekend? (if it’s early in the week).

Once the participant has left, make sure the tape is labeled. You need to label the tape with:

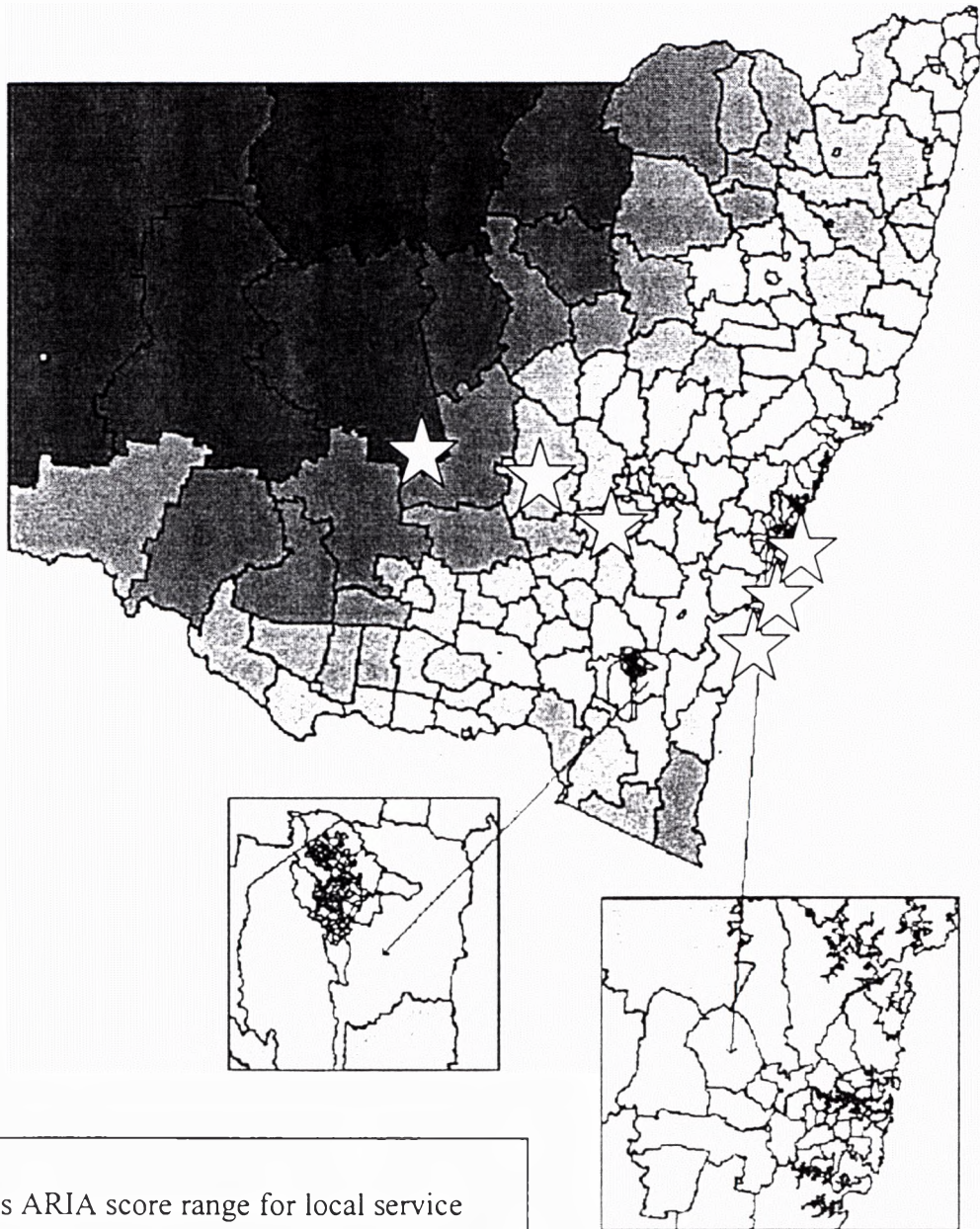
- The date
- Time of interview
- Your initials

Put the tape into the manila envelope with the forms the participant completed.

## APPENDIX C

MAP OF NEW SOUTH WALES & AUSTRALIAN CAPITAL TERRITORY  
SHOWING APPROXIMATE LOCATIONS OF STUDY 1 INTERVIEWS

From: Commonwealth Department of Health and Aging, 2001, Canberra.



NOTES:

Shading indicates ARIA score range for local service areas, with lightest shading indicating low ARIA scores, and darkest indicating high ARIA scores (scores range from 0 – 12).



indicates approximate sites of interview locations for Study 1.

## APPENDIX D

### CONSUMER RESEARCHER FOCUS GROUP GUIDE, STUDY 2



## FOCUS GROUP GUIDE, STUDY 2

## Introduction:

As you have read, my aims for our focus group today are for us to look back at the themes that came from the CEO-MHS interviews in the context of your experiences as researchers on the project.

So what I'm interested in discussing today is whether any of these themes have been personally relevant to your experiences as a CR –not your experiences as a consumer with public MHS, but as a researcher involved in the CEO-MHS project.

Clarify aims & purpose: check understanding

Answer any Questions

- The theme of **stigma** came up in the interviews, and related to people's experiences of stigma within and beyond services. **I'm wondering what you have to say about stigma, in relation to your experiences as a CR in the project?**
- Another theme that came from our interviews was about **information and education**. Again this theme captured many differing aspects – whether information was accessible or not to consumers; if information was reliable or not; if consumers felt they were kept informed about things or not; that the education of staff influenced consumers experiences, as does the level of expertise

or knowledge staff have; and education and information in relation to the community was also discussed.

**Thinking about your experiences as a CR, what role has information and education played for you?**

- People in our interviews also talked about **power and powerlessness**, in terms of a personal sense of having a sense of power or control – or not. Often people spoke about feeling powerless in their experiences with mental health services, but other's spoke about feeling a sense of control as well. **What have your experiences with a sense of power or powerlessness been, in your role as a CR?**
- A theme, which we called **Consumer involvement**, came up in CEO-MHS interviews. This theme represents discussions participants had about their desire to be involved in all levels of MHS. Part of this related to their concern for other's who are (or will be) in contact with a MHS. Some people spoke about barriers they faced within MHS, to reaching the level of involvement they wanted. What came through in these discussions also was a belief that being involved was linked to creating better services and a sense of hope – for themselves and others. **I'm wondering what you have to say about consumer involvement, in relation to your experiences as a CR in the project?**

- Participants in our interviews spoke about medication, and the role this plays in their experiences with services. **I'm wondering if medication has been an important issue for you in your experiences as a CR? If so, tell me more about this?**
- Another theme in our CEO-MHS interviews is system issues. This theme really relates to things at an organisational level. For example, things linked to resources; staffing levels; safety; environment. **Thinking about your experiences as a CR, what role have system issues played for you?**
- The theme "responsive to consumers" captures discussions within interviews of the need for services to be responsive to consumers – that the purpose of mental health services is to *serve* consumers. At the core of this theme is the question of who decides what is needed for any consumer, how choices are made, and who's needs are being met in the process. Some consumers' spoke about services playing a positive role in terms of being responsive to them, others spoke about a lack of responsiveness in their experiences. **Has this theme, of being responsive to consumers, been important in your experiences as a CR? If so, tell me more about this.**
- Relationships with staff, particularly in terms of staff attitudes and the way consumers felt they were treated by staff, was another theme in our CEO-MHS

interviews. **Has this been important in your experiences as a CR on the project? If so, how/ in what way?**

- **Relationships with community, other consumers & family** was another theme that came from our interviews with consumers. Part of this theme related to experiences of isolation & community broadly as well. **What role has a sense of isolation and community – and relationships with community, family and consumers – played in your experiences of being a CR?**
- Another theme that emerged from the interviews we called **“all of me”** to group different discussions relating to a sense of person beyond mental illness, and specific diagnosis, conveyed by participants in the interviews: in other words the whole person. Some aspects of this theme related to sub-themes like the need to have opportunities to achieve; exploration of issues for self –coming to greater self-understanding; learning skills to manage both symptoms and life; cultural sensitivity; to be seen as a person; work force retraining. **While participants spoke about these things in relation to their experiences with MHS, I’m wondering if you feel this theme relates in any way to your experiences in this project? If so, how/in what way?**
- The final theme in our analysis of CEO-MHS interviews was **diagnosis**. This theme is fairly self-explanatory, in that it relates to participants having talked about how their diagnosis impacted on their experiences with MHS. **I’m**

**wondering what you have to say about diagnosis, in relation to your experiences as a CR in the project?**

## APPENDIX E

INSTRUCTIONS AND TEMPLATE PROVIDED TO CONSUMER RESEARCHERS  
TO COMPLETE 'SNAKE' OR 'WINDING RIVER' CHART FOR INTERVIEW 1,  
STUDY 2

### Instructions for completing 'snake' chart

Use the sheet provided, which outlines different stages or 'landmarks' of the CEO-MHS project.

Using this sheet, draw a representation of your experience of being part of this project, as a CR. To do this, draw a winding 'snake' or 'river', with each turn in the snake representing a **personal experience that has been critical to you in your experience as a CR.**

You might find some of the landmarks on the sheet become 'bends' or 'turns' in your snake, while others may not – you might find that none of the 'landmarks' represent critical moments for you, instead being straight parts of your river.

When 'bends' fall at other places on this sheet, where there isn't a project 'landmark', write a brief description, or heading for this bend.

Use the landmarks on the next sheet in whatever way they fit best with your experience. They will help keep the time sequence of the project.

Interview for 'CR' position

Original 3 day Training (2001)

Developing Focus Group questions etc

Facilitating focus groups

Interpretation of F/G data & validation of qualitative analysis

Developing Interview Questions & Format

Additional/refresher training (2002)

Training in using PowerPoint

TheMHS 2002

Deciding sampling for interviews

Conducting Interviews

Analysis of Interview data

Developing Evaluation Framework



## APPENDIX F

### EXPERIENCE CYCLE METHODOLOGY PROCEDURE FOR INTERVIEW 2 WITH CONSUMER RESEARCHERS, STUDY 2

## EXPERIENCE CYCLE

I want you to tell me a story about what it's been like for you to be involved as a consumer researcher with the CEO-MHS project.

### Anticipation

- What things were you expecting would happen?
- What options did you see open to yourself at this time?
- Were there particular things that concerned you? (what were they?)

### Investment

- How much did you want this prediction to come true or not come true?
- How much did it matter to you at the time?

### Encounter

- Describe the actual experience of being involved – good and bad.

### Confirmation/Disconfirmation

- How have things gone compared to how you initially thought they would?
- How did the prediction go?
- What feelings do you have about this?

### Constructive Revision

- In general, what things have you learnt from this experience?

## APPENDIX G

### LET'S JUST SAY' PROCEDURE FOR INTERVIEW 2, STUDY 2

**LET'S JUST SAY**, adapted from Epting et al (1991)

- ❖ Let's just say a consumer was applying for a position as a researcher on a project similar to CEO-MHS. How might they be feeling? What would they be thinking? How would they see themselves?
  - How would they feel when they find out they are successful? What would they be thinking? How would they see themselves?
  
- ❖ Let's just say a consumer researcher is participating in a group training session as part of this project, learning about data collection methods, with other consumer researchers. How might they be feeling? What would they be thinking? How do they see themselves?
  - When the training is finished, how would they feel? What would they be thinking? How would they see themselves?
  
- ❖ Let's just say a consumer researcher is about to run their first interview with another consumer, about their experiences of public mental health services. How might they be feeling? What would they be thinking? How would they see themselves?
  - How would they feel once the interview is finished? What would they be thinking? How would they see themselves?
  
- ❖ Let's just say a consumer researcher is involved in preparing written documents reporting on an aspect of the research, to present at a conference. How might they be feeling? What would they be thinking? How would they see themselves?

- When the documents are complete, how would they feel? What would they be thinking? How would they see themselves?